

# REPORT

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Final Report

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## **Development of an Evaluation Strategy for State-Based Diabetes Control Cooperative Agreement Programs**

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To

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Centers for Disease Control and Prevention

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1600 Clifton Road

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Atlanta, Georgia 30333

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October 1997

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**Final Report**

**Contract No. 200-93-0626**

**on**

**"Development of an Evaluation Strategy for State-Based Diabetes Control Cooperative Agreement Programs"**

**to**

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## Executive Summary

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**Title:** Development of an Evaluation Strategy for State-Based Diabetes Control Cooperative Agreement Programs

**Contract Number:** 200-93-0626, Task 06

**Sponsor:** Division of Diabetes Translation  
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### Statement of the Problem

Diabetes Mellitus and related complications are a major cause of morbidity and premature mortality in the United States. Diabetes was the seventh leading cause of death listed on US death certificates in 1993. Its estimated economic cost was \$92 billion in 1992 in both direct and indirect medical costs (ADA, *Diabetes Info*, 1997). The Centers for Disease Control and Prevention (CDC) has been supporting Diabetes Control Programs (**DCPs**) since 1977. The underlying premise of these programs is that the health consequences of diabetes can be substantially reduced by effective, widespread clinical and public health applications of preventive programs. In 1997, there were **DCPs** in 50 states.

In 1994, the DCP was expanded from 27 to 42 states. At the time of this expansion, the program also shifted its approach from one of reducing complications of diabetes by direct services to persons with the disease, to an approach emphasizing core public health functions of leadership and advocacy. The purpose of this approach is to effect changes in the health system responsible for providing preventive services, education, and care to people with diabetes, or at risk for diabetes.

pp 5-6

### Evaluative Objectives

The *goal* of the study discussed in this report was to develop an evaluation strategy for state-based Diabetes Control Programs that was based on (1) a set of lessons concerning diabetes services and advocacy within an evolving health systems

environment and (2) knowledge of the current resources of **DCPs**. Battelle sought to achieve this goal by:

- Developing evaluation questions based on priority capacity building and infrastructure indicators for **DCPs**.
- Implementing a survey that yields a report on the progress made by **DCPs** in core capacity building and infrastructure development.
- Identifying key health system change issues in the area of managed care to generate lessons relevant for **DCPs**, considering their capacity and resources, and for members of the Division of Diabetes Translation who assist **DCPs**.

The centerpiece of this report is the presentation of findings from a survey sent to 42 state-based Diabetes Control Programs. The **objectives** for the survey were to:

- Describe the infrastructure elements that are currently present in **DCPs**.
- Demonstrate, if possible, the relationship of infrastructure to programmatic processes and outputs.
- Make recommendations for a strategy that includes ways of measuring programmatic outcomes from which credible inferences can be made regarding the impact of DCP activities on the public health.

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### **Methodology**

The present study was preceded by a feasibility study that resulted in a framework of indicators for a survey of 42 state-based **DCPs**. These **DCPs** were chosen because they were all funded early in the present funding cycle. Then we pilot tested the survey instrument developed from the framework in three states that represented different geographic locations and varied experience with managed care plans. Finally, we implemented the survey sending it to the person responsible for the DCP in each state, either the Program Coordinator or Program Director. We attained a **100** percent response rate. In addition to the survey, an exploratory study of collaboration between selected **DCPs** and managed care organizations was undertaken in order to **contextualize** some of the survey findings (Birch and Davis, April 1997).

Data were entered into a **Microsoft Access** database. We developed frequencies for all quantitative data, as well as cross-tabulations and tests of statistical significance where appropriate. Qualitative data were content-analyzed and coded. Written comments that illustrated issues that were especially variable across states were entered into the database verbatim. The findings are based on an interpretation of the quantitative results in light of the content-analyzed and verbatim responses.

## Major Findings and Recommendations

**Infrastructure and Core Capacity Elements** - Infrastructure elements are those resources necessary for implementing a state DCP- human, financial, and in-kind contributions - and the organizational structure in which the DCP operates. Core capacity elements extend infrastructure so that programmatic efforts can be carried out. In this view, we were especially interested in the use of advisory structures and in strategic planning.

We found that:

- State-based **DCPs** generally have small staffs, many of whom are shared with other departments, programs or branches within the state health department. Some **DCPs** have been without a dedicated **DCP-only** Program Director or Program Coordinator for varying periods of time throughout the present funding cycle.
- About three-fourths of the **DCPs** had either epidemiologic support or surveillance support, and four states had both. Twelve **DCPs** lacked any epidemiologic or surveillance staff. Most other categories of staff appeared to have an educational or outreach function.
- Most **DCPs** were heavily dependent on the CDC Cooperative Agreement for funding in 1995 and 1996, with 33 (79 percent) receiving between **three-fourths** and all of their funding from CDC in both of those years. The next most common source of funding was state prevention block grant **funds**, followed by other types of state funding. With the exception of two states, the amount of these contributions from state sources was low. Six **DCPs** received funds from federal sources other than CDC, and a few **DCPs** also accessed small amounts of funding from pharmaceutical companies or other non-governmental sources.
- **DCPs** are adept at leveraging in-kind support, most frequently from **diabetes-related** voluntary organizations, pharmaceutical companies, and hospitals or medical centers. Managed Care Organizations (**MCOs**) provided in-kind support in eight cases. The types of support tended to be logistical (e.g., meeting or conference space) as well as donated labor or service, educational materials, and miscellaneous equipment.
- A major strength of the DCP is its ability to build partnerships. This strength is evidenced by (1) collaborations with other state health department agencies, (2) other agencies in the state government, and (3) advocates and others outside of state government.
- Within the state health department, the most common type of collaboration was with the Chronic Disease Division, often on committees of an administrative nature. Nearly half of **DCPs** collaborated with the state office responsible for Medicaid or Medicaid Managed Care. Outside the state health

department, slightly more than half of the collaborations were with the Department of Education. Just under half of the **DCPs** said that they had been involved in a collaboration with the State Legislature. Common types of collaboration outside of state government deal with diabetes education, advocacy, or outreach.

- Forty-one of the 42 **DCPs** have an advisory body, usually carrying the designation Advisory Council, although two were inactive at the time of the survey. Coalitions and Work Groups are also common types of advisory groups. Most advisory groups have subcommittees that tackle specific efforts. The kinds of activities undertaken include: development and distribution of standards or guidelines for care, screening and education; development of goals and objectives for diabetes control; patient education and health promotion activities; legislative efforts; data collection, analysis, and dissemination; development of a guide to diabetes resources and benefits; and fund-raising or coalition-building.
- Data from 25 of the 42 **DCPs** show that the most common category of new advisory group members consists of representatives of non-profit and advocacy organizations, especially those that are diabetes-related. A number of states are working with Medicaid, insurance plans, the managed care industry, and peer review organizations.
- Over half of **DCPs** (**n=24**) have a completed strategic plan, with the majority completed in 1994 or later. While we only asked directly about completed strategic plans, three **DCPs** volunteered that diabetes strategic planning was currently in progress. It may be that others would have reported this process had we asked specifically about ongoing planning.
- Most **DCPs** are working towards several objectives at any one time. We did not see much evidence of evaluation of the objectives for outcomes. A few states are using “recommendations” instead of objectives. We were told that recommendations are meant to be ongoing throughout the strategic planning cycle.

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**Surveillance and Use of Data** - At a minimum, state **DCPs** must be able to obtain, analyze, and use data to define and monitor the burden of diabetes. Our survey was mainly concerned with data sources available to **DCPs** and with barriers to data access. Since use of surveillance and other data should be linked to program goals and objectives, we also sought evidence of dissemination of data and its use for program planning and evaluation.

We discovered that:

- Virtually all **DCPs** utilize the diabetes module of the BRFSS. The trend towards use of the module has been increasing since 1994. Through looking at data submitted from 11 states, we see that the sample sizes for the diabetes

module are very small, ranging from 50 in a less populous state to 200 in an extremely populous state.

- Most **DCPs** were able to use the following key indicators from the main body of the BRFSS: exercise, cardiovascular disease, smoking and nutrition. **DCPs** with their own epidemiological support were more likely to analyze BRFSS data on an annual or biannual basis than those without such support.
- Sixteen **DCPs** supplemented the BRFSS with targeted surveys mainly geared to learning about particular underserved populations within their states.
- The most common types of data sources used by **DCPs**, aside from the BRFSS, were death certificates, hospital discharge information, birth certificates, and end-stage renal disease (ESRD) registries. **DCPs** had difficulties accessing proprietary data sources such as the Health Plan Employer Data Information Set (HEDIS) and pharmaceutical databases, although a few were able to do so. Blindness registries and diabetes registries were very rare.
- **DCPs** disseminate data in both written and oral forms to a variety of audiences. The main audience for written information is health care providers, and for oral information, fellow conferees at diabetes, public health or chronic disease meetings.

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**Health Systems Change** - Coordinating the overall efforts of the health system to reduce the burden of diabetes is an important part of the work of state **DCPs**. We were particularly interested in whether there is evidence that the partnerships **DCPs** establish with other agencies and organizations do, indeed, extend the program's reach to other sectors in the state, both public and private. The kinds of data we used include brief descriptions of activities to extend access to education, resources, or care and to improve quality of care through education or dissemination of guidelines and standards.

We learned that:

- More than half the **DCPs** have conducted some kind of surveillance, programmatic or advocacy activity with Medicaid since July 1, 1994. Exactly half of the **DCPs** have had some type of interaction with the agency in the state that regulates insurance, and the same number for the agency responsible for regulating **MCOs**. (There is overlap in these two agencies.)
- About a quarter of **DCPs** are obtaining data from **MCOs**, including quality assurance, quality control and quality improvement (**QA/QC/QI**) data. These data have been used for planning or evaluative purposes.
- **DCPs** provided substantial information showing variations in Medicaid coverage for diabetes-related education, supplies or care across states. Insulin and other medications were covered in almost all states, followed by

monitoring equipment. There were fewer limitations on coverage of insulin than for other medications, or for monitoring equipment. Half the states covered therapeutic shoes, and fewer than half the states covered outpatient education for some or all of their Medicaid patients.

- **DCPs** cited many activities, conducted **with** partners (voluntary agencies, state agencies, their advisory groups, hospitals or **medicals** schools, and academic institutions), meant to increase coverage of outpatient education and supplies. Also common were efforts to increase coverage of medical services.
- The most common method for increasing coverage was through influencing legislation through work with partners. A frequent challenge was the time needed to build consensus around legislative issues.
- **DCPs** worked with partners to disseminate, update or draft standards and guidelines. The most common target for standards or guidelines was physicians or other medical providers. In addition, we received examples from 19 states of initiatives regarding standards and guidelines that were specifically targeted to **MCOs**.

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#### **Efforts and Activities in Health Communications and Community-Based**

**Activities** - A brief series of survey items concerning health communications was enfolded into the portion of the questionnaire that dealt with core capacity. In the past year, CDC has been increasing **the** technical support that it gives to **DCPs** to implement health communications activities. The data we received, though not comprehensive, indicated a greater move towards incorporating such efforts into the overall programmatic functions of the DCP **than** we had originally anticipated. **DCPs** may implement statewide or community-based health communications activities, or both.

For example:

- All but four **DCPs** have engaged in some type of health communications activities since July 1, 1994, the majority in partnership with another group.
- The types of activities varied widely. **DCPs** use such media as radio, television, and print. The DCP may work on specific campaigns or on other activities, such as town hall meetings on diabetes. Community-based activities were those that were meant to disseminate diabetes education at the local level (including, but not limited to, **Diabetes Today**), or that were specific **DCP**-supported demonstration activities.
- About half of states gave examples of local or community-level activities. These **DCPs** tend to have multiple projects or programs in several communities. Target audiences may be either consumers (including families of patients), health care providers or the general public, or a combination of all three.

- Activities tended to be targeted to specific populations such as African Americans, Native Americans, seniors or others.

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### Summary of Programmatic Efforts

Overall, we saw the DCP as a program with a number of strengths, as well as some weaknesses. **DCPs** are active and comfortable in coordinating activities, mainly through their advisory groups, although they work with other partners as well. Because DCP staff are forbidden to lobby, partners have been critical in advocating for policy change through legislation.

The **DCPs** have been making considerable efforts towards defining the burden of diabetes through monitoring and surveillance. Even programs with limited access to epidemiologic support obtain data from a number of sources, including but not limited to the BRFSS. However, there are limitations inherent in the tools most easily accessible to **DCPs**. A more effective system to monitor the burden of diabetes within an underserved population should enhance the ability of programs to do strategic planning, an area that still requires strengthening.

Our questionnaire frequently asked for examples of accomplishments but, for the most part, did not focus on the development of new programs. Our impression is that **DCPs** were very much concerned either with starting up the state program (17 states in the sample) or with meeting the demands of the new cooperative agreement (that is, of being a public health leader rather than a direct service provider). Furthermore, with regard to implementation of new programs, it may still be another year or so before clear evidence of such implementation is apparent. This is largely because (1) the focus of the DCP has changed considerably since 1994, and (2) many states were new to the program during this funding cycle.

pp 105- 108

**Recommendations for Strengthening Programmatic Efforts:** Our recommendations are ones that we believe can be accomplished, even within the infrastructure restrictions with which most **DCPs** must cope. For each recommendation we make, we can name one or many states that already practice it or technical assistance (TA) at national meetings that has addressed the need. Therefore, we begin with a recommendation to:

- Strengthen and increase venues for DCP staff to teach each other about their successes - and their failures.

Other recommendations are:

- Technical assistance should emphasize that all activities - health communications, local or community-level education and demonstration projects - have an impact on the health system. For example, a consumer who is informed about appropriate screening through community-based training knows to demand this service from his or her provider. In this way, all program activities are meant to have an impact on the system for delivering

prevention and health services to people with diabetes, or at risk for the disease, even if this is done indirectly.

- Disseminate information on creative ways developed by state DCPs to strengthen infrastructure and core capacity. For example, one state has used grants for university-based researchers to supplement frozen positions in the DCP.
- In the area of health communications, DCPs should receive technical assistance concerning ways of using techniques to target audiences, to develop a profile of audiences, and to evaluate the impact of a message or intervention on the target.
- Health communications technology should be used to enhance the visibility and stature of the diabetes program within the state as a way of gaining attention for the problem of undiagnosed or under-treated diabetes. This includes teleconferences, town hall meetings, and use of print media. Most of our recommendations have dealt with technical assistance. We also make a recommendation to:
  - Integrate evaluation into programs such that all objectives and all activities to meet those objectives are based on data and lead to a measurable outcome.

pp 112-119

**Recommendations for Developing an Evaluation Strategy.** DCPs are required to develop objectives and ways of evaluating those objectives when they apply for CDC funding. In addition, just over half of states now have strategic plans for diabetes. We believe that all states should engage in strategic planning for diabetes. Designing the process may take time, especially since objectives need to be developed in partnership with state health department staff and advisory partners and other stockholders. If the DCP does not have its own surveillance staff, baseline data must be obtained through the staff of other departments. Once the process is in place, though, time spent on evaluation is incorporated throughout the activities of the DCP.

One way of keeping the process of strategic planning within limits that are realistic for DCPs, given their small staffs, is to focus the process on two key questions:

- How are the activities for meeting each strategic planning objective improving access ?
- How are the activities for meeting each strategic planning objective improving quality? We believe that by focusing on improving access and quality, the DCP will have a strong impact on the health system, provided that those who are without access or sufficient quality of services are identified. When speaking of access or quality we refer to objectives that affect the health system throughout the continuum of prevention - primary, secondary, and tertiary.

One way of keeping track of progress toward meeting objectives would be to individualize progress reports so that they contain strategic planning objectives and benchmark indicators for meeting those objectives. The reports could contain topic

headings, such as surveillance and use of data, health systems change, health communications, and community-level activities. Each state could supply its own strategic planning objectives and document progress towards meeting them through process and outcome measures. Also, **the DCPs** could cite barriers if progress has been slow or make a statement if the objective is being put aside.

**Assessing Outcomes.** One challenge is developing assessment questions for a multiplicity of programmatic approaches. We have come to the conclusion that variety is not a hindrance to evaluation and program planning so long as basic criteria are met. We believe that each of the criteria suggested above can lead to measurable programmatic outcomes in line with the processes identified in the present study. These outcomes can be part of the measures of objectives identified through strategic planning and expanded upon during full-scale evaluation activities. The DCP can then have an impact on the health of a state through incremental outcomes that are linked with efforts carried out by other members of the health system.

In order to do this, we need to ask what the health system must be able to provide for people **with** diabetes. We suggest four broad criteria:

- The system provides technically and culturally competent health education.
- The system provides access to and use of basic preventive services.
- The system assists patients to comply with diabetes control measures including early detection and follow-up to prevent or delay onset of complications.
- The system provides access to and use of cost-effective clinical services for complications and their follow-up to prevent or delay progress from mild to severe complications or death.

These criteria would hold whether the patient enters the health system through Medicaid, a managed care organization, or a private provider. They also hold whether objectives are targeted to the health system in the state, to a community, or to local-level providers.

**Assessing Impact on a State and National Level.** While recognizing that limitations in drawing conclusions about the impact of each DCP on its state and of **the DCP** as a whole on the nation's health, will continue to exist, we suggest a **continuum** of activities that should yield defensible inferences about such impact. The continuum consists of:

- An assessment that provides a reasonable estimate of the proportion of the state's population who are at risk of acquiring or already have diabetes, but who do not have access to the technologies capable of preventing and/or controlling the disease or its complications.
- As part of the assessment, instruments that help characterize underserved populations.

Who are these populations?

Where do they live?

What factors are impeding their access to the appropriate technologies?

What resources are available that could be mobilized to improve their access to the appropriate technologies?

- Based on the data obtained from the assessment, **DCPs** can develop realistic objectives. These objectives should be clearly defined. Objectives should state how they will be achieved, by whom, and with what resources.
- **DCPs** need to identify which indicators provide the best estimates of progress toward defined objectives. This implies developing indicators and instruments that are particularly sensitive for measuring changes that occur in underserved populations. Statewide averages may be misleading, since underserved populations are under-represented in provider-based surveys. This is partly because underserved populations are easily missed in surveys, especially those that use the telephone. Many other barriers, such as language, culture, mobility, unsafe neighborhoods, geographical isolation, and illiteracy contribute to the under-representation of underserved populations in conventional data gathering for program monitoring and evaluation.
- Despite their limitations, data gathered using non-targeted approaches, could be **used** if care is taken to avoid the pitfalls of these data. For example, the diabetes module of the BRFSS could ask when the interviewee was diagnosed with diabetes and whether he or she had complications at that time. This would provide an indirect measure of whether early disease detection (screening of high-risk populations) was being effective. Other questions could ask about self-management of blood glucose and patient education.
- Data from states on their target populations could be kept in a national database so that trends can be monitored.

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**Conclusion.** We believe that **DCPs** should be encouraged to grow in ways that are appropriate to their own states. In the future, by linking these outcomes to the pragmatic activities, it should be possible to demonstrate an impact on diabetes and its complications. In this way, **DCPs** can become more visible players in their states by influencing health systems to improve access to care and quality of care for all people with diabetes, or at risk of the disease. Ultimately, this will lead to a better public **health environment**.

**1.0 Introduction-Background, Study Purpose  
and Study Approach**

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## 1 .O Introduction-Background, Study Purpose and Study Approach

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In this chapter we discuss the background for the present study including a very brief history of the Diabetes Control Program (DCP). We do this in the context of some recent developments in clinical science and public health that are affecting the delivery of population-based diabetes control services. We then present the study purpose with its goals and objectives and its limitations in terms of assessing health, and to some degree, programmatic outcomes. The largest portion of the chapter is devoted to the survey approach, which is the central source for this report. We end with an overview of the organization of the remainder of this document.

### 1.1 General Background and History

Diabetes Mellitus and related complications are a major cause of morbidity and premature mortality in the United States. Diabetes was the seventh leading cause of death listed on US death certificates in 1993. The estimated economic cost in both direct and indirect medical costs was \$92 billion in 1992.<sup>1</sup> Approximately 8 million Americans have been diagnosed with diabetes, and another 8 million Americans are thought to have undiagnosed diabetes.<sup>2</sup> Diabetes is a leading cause of new blindness and end-stage renal failure in the United States and a major co-morbid factor in lower extremity amputation, cardiovascular disease and related death, and neonatal morbidity and mortality.

The Centers for Disease Control and Prevention (CDC) has been supporting Diabetes Control Programs (DCPs) since 1977. The underlying premise of these programs is that both secondary prevention efforts (e.g., **glycemic** control, nutrition counseling) and tertiary prevention strategies (e.g., appropriate screening for and treatment of complications) are efficacious in reducing the burden of diabetes. In other words, the health consequences of diabetes complications--blindness, amputations, kidney failure, adverse outcomes of pregnancy--can be substantially reduced by effective, widespread clinical and public health applications of preventive programs.

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<sup>1</sup> American Diabetes Association (ADA) "Diabetes Facts and Figures" in *Diabetes Info.* <http://www.diabetes.org/ada/c20f.html>. 1997

<sup>2</sup> The Diabetes Council. *Building Resources.. A manual for the diabetes advocate.* (Information c.f. CDC) Association of State and Territorial Chronic Disease Program Directors (ASTCDPD). March 1997.

Until 1994, the **DCPs** were demonstration projects. **At** this time, several factors converged on the clinical front and in the health system environment. The outstanding clinical factor was the results of the Diabetes Control and Complications Trial (DCCT). The outstanding health systems event was the failure of national health care reform and the shifting of health care reform efforts to states.

The DCCT established that the onset, development, and progression of diabetes complications can be substantially delayed and reduced by rigorous **glycemic** control. The near decade-long trial followed 1,441 patients between the ages of 13 and 39 years who had Type 1 diabetes. It established that “the incidence of retinopathy, nephropathy and neuropathy could be reduced by intensive treatment.”<sup>1</sup> Logically, scientists surmised that similar rigorous control could decrease complications in people with Type 2 diabetes.

Translation of these clinical findings to the public health arena presents many challenges, some of which **DCPs** are uniquely poised to meet. There are estimated to be more than seven million Americans with Type 2 diabetes. Reaching this many people requires the coordination of numerous public health and clinical practitioners from different disciplines, and it requires an awareness of the difficulties that primary care practitioners face when working with such a complicated multi-system disease. For example, there is concern that tight control can lead to hypoglycemic episodes in those people who are not monitoring themselves closely. For people with Type 2 diabetes, hypoglycemia is associated with obesity, a major problem in managing the **disease**.<sup>2</sup> Hence, the need for self-management education and compliance with diet and exercise plans. This one illustration (simplified as it is) demonstrates the need for people with varied professional backgrounds to be involved with public health initiatives to reduce the burden of diabetes.

Clinical progress continues, leading to hopes for primary prevention and new recommendations for early detection. In the summer of 1997, an international committee working under the sponsorship of the American Diabetes Association (ADA) established new guidelines for the detection and classification of diabetes. These guidelines recommend that every **adult** age 45 and older be screened for diabetes using a fasting plasma glucose (FPG) test. An FPG of 126 **mg/dl** or above would mean a diagnosis of diabetes, provided it was confirmed through a second FPG on another day. Formerly, diabetes was diagnosed

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<sup>1</sup> **Clark, Charles M, D Anthony Lee. “Prevention and Treatment of the Complications of Diabetes Mellitus” in *New England Journal of Medicine* (NEJM), May 4, 1995, Page 1210.**

<sup>2</sup> **Fertig, BJ, DA Simmons, DB Martin. “Therapy in Diabetes” in *Diabetes in America*. National Institutes of Health (NIH), National Institute of Diabetes and Digestive and Kidney Diseases (NIDDKD). NIH Publication No. 95-1468, 1995.**

through the more complicated and time-consuming oral glucose tolerance test (OGTT). The newer guidelines allow for a greater likelihood of identifying people with diabetes so that they can receive education and treatment before vascular changes, which lead to complications, occur.’ Other guidelines address the identification of impaired glucose tolerance (IGT) and gestational diabetes (GDM). In short, DCPs are now operating in an environment where early intervention to avoid complications of diabetes, and possibly even to prevent its onset, is feasible. Historically, though, such intervention has been challenging.

Data from earlier studies of national trends showed that it is likely that prevention strategies are not being adequately or widely implemented in clinical and public health practice. For example, National Health Interview Survey (NHIS) data from 1989 “showed that only a minority of people with diabetes in the United States (35%) have taken an educational class or program”.’ For these and similar reasons, CDC believed that it would be essential for the public health community to assume a leadership role in understanding and reducing the gap between what should be and what is the current standard of diabetes care. And, in fact, a major focus of a number of state-based Diabetes Control Programs (DCPs) has been to increase the access of people with diabetes to patient education.

Clinical, patient education, and public health efforts all occur within a health care system. The health systems environment, never static, has been in a state of flux during the 1990s. The decade began with a move towards national health care reform, and then in the mid-1990s, attention shifted to states and managed care organizations (MCOs). Public health leadership in reducing the burden of diabetes within the changing health system involves all segments of populations affected by diabetes - persons with diabetes, health care providers, public health practitioners, and others active in diabetes-related issues. Coordination of efforts in such areas as ensuring access to care, quality assurance, appropriate use of available services and facilities, and assessment of health outcomes, represent emerging opportunities to ensure the efficient application of effective diabetes prevention programs.

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<sup>1</sup> **The Expert Committee on the Diagnosis and Classification of Diabetes Mellitus. “Report of the Expert Committee on the Diagnosis and Classification of Diabetes Mellitus” in *Diabetes* 20 (7) 1183 ff. July 1997, [http://www.diabetes.org/diabetescare/1997-07/pg\\_1183.htm](http://www.diabetes.org/diabetescare/1997-07/pg_1183.htm)**

<sup>2</sup> **Ibid. Page 528.**

CDC further suggested that, to reduce the burden of diabetes within a reformed health system, the public health community must address three broad areas:<sup>1</sup>

- Improving the quality of health data and simplifying the processes of data collection and analysis to serve the needs of both the clinical care system and population-based public health approaches;
- Assuring access to care for underserved and “at risk” populations; and
- Strengthening “core” public health functions, such as disease surveillance and monitoring, public information and education, and assurance of high quality care, while meeting health needs of regional or national significance.

These recommendations sum up the health systems approach that has formed the cornerstone of the DCP since late 1994.

### 1.1.1 Evolution of the Diabetes Control Program

Recent efforts to reduce the burden of diabetes build upon **two** decades of programmatic activities. The Department of Health and Human Services (DHHS), Public Health Service (**PHS**), and Centers For Disease Control and Prevention (CDC) established State-Based Diabetes Control Programs (**DCPs**) in 1977. Initial activities (1977-1985) focused on state-specific needs assessment and on patient and professional education. In more recent years (**1986-1994**), state-based activities incorporated emerging science associated with control of diabetes-related complications (eye disease, lower extremity disease, cardiovascular disease, adverse outcomes of pregnancy).

The 1994 Request for Applications (RFA) entitled “State-Based Programs to Reduce the Burden of Diabetes: A Health Systems Approach” sought to refocus the efforts of **DCPs** from direct service provision to a leadership and quality assurance role consistent with health care reform. It was in this context that CDC expanded the DCP to cover most states in the US and several US-affiliated jurisdictions in the Pacific region. The RFA was organized around the following four principles:

- **Define and monitor the burden of diabetes.** This element enjoins states to establish and maintain a state-based surveillance system focusing on diabetes as a public health problem.

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<sup>1</sup> **Division of Diabetes Translation. *State-Based Programs to Reduce the Burden of Diabetes: Guidelines for Program Design, Implementation, and Evaluation*. National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, March 1994.**

- **Develop new approaches to reduce the burden of diabetes.** Here states are requested to focus on both “the existing and the evolving health care system.”
- **Implement specific measures to reduce the burden of diabetes.** This element cross-cuts educational and programmatic activities and may require leveraging resources beyond the cooperative agreement.
- **Coordinate overall program efforts of the health system to reduce the burden of diabetes.** This element emphasizes the leadership function of public health in the system change paradigm.

The health system continues to develop, even as we write, with new initiatives in the public health and clinical sectors. For instance, CDC now has additional resources to spend on professional and patient education through a recent Congressional appropriation.<sup>1</sup> Also, CDC is expanding its comprehensive Diabetes Control Program. In 1994, two states (Michigan and Minnesota) were funded as “enhanced capacity programs,” meaning that they received funds beyond the “core” cooperative agreement for enhancing surveillance systems in a way that data could be used to further the purpose of the diabetes program. Michigan focused on developing local capacity, and Minnesota, on working with managed care systems. In 1997, several more states are competing for “comprehensive” funding in one or more of the areas of health systems, health communications, or community-based programming. Thus, it is apparent that the DCP continues to evolve.

## 1.2 Study Purpose

The remainder of this document is a report of a project concerned with a model evaluation strategy for state-based diabetes control programs (**DCPs**). The evaluation strategy is based on the results of the following activities: (1) developing an evaluation plan in conjunction with advisors from state **DCPs**, state-based Divisions for Chronic Disease Prevention and Control, and CDC; (2) a survey of the 42 state-based **DCPs** funded since late 1994; and (3) a special study in the area of health systems change.

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<sup>1</sup> American Public Health Association (APHA). “CDC to receive more resources to spread the word about diabetes” in *The Nation’s Health*, August 1997, page 7.

### 1.2.1 Goal, Method, and Objectives of the Present Study

The goal of the present study is to develop an evaluation strategy for state-based Diabetes Control Programs that is based on (1) a set of lessons concerning diabetes services and advocacy within an evolving health systems environment and (2) knowledge of the current resources of state-based diabetes control programs. Battelle sought to fulfill this goal by the following *methods*:

- Develop evaluation questions based on priority capacity building and infrastructure indicators for **DCPs**.
- Implement a survey that yields a report on the progress made by **DCPs** in core capacity building and infrastructure development.
- Identify key health system change issues in the area of managed care that will generate lessons relevant for **DCPs**, considering their capacity and resources, and for members of the Divisions who assist **DCPs**.

The centerpiece of this report is the presentation of findings from a survey sent to 42 state-based Diabetes Control Programs, which yielded a **100** percent response rate. The *objectives* for the survey were to:

- Describe the infrastructure elements that are currently present in **DCPs**.
- Demonstrate, if possible, the relationship of infrastructure to programmatic processes and outputs.
- Make recommendations for a strategy that includes ways of measuring programmatic outcomes from which credible inferences can be made regarding the impact of DCP activities on the public health.

## 1.3 Survey Approach

This section presents our approach to meeting the goal and objectives of the study. We began with a feasibility study **that** resulted in a framework of indicators. Then we pilot tested **the** survey instrument developed from the framework, and finally we implemented the survey.

### 1.3.1 Feasibility Study

It was the experience of both Battelle and CDC that **DCPs** are varied in their approaches to decreasing the burden of diabetes.<sup>\*\*\*</sup> Prior experience in developing evaluation approaches showed that a prescriptive approach to evaluation would not be feasible given the variability in state programs. Therefore, Battelle and CDC convened a work group of state DCP staff with expertise in epidemiology, surveillance, programming, and coordination. The work group met monthly from December 1994 until May 1995, either by telephone or in person. State-based representatives came from California, Minnesota, New York, Texas, West Virginia and Washington. They held positions such as Chief of Chronic Disease, DCP Coordinator, Epidemiologist, Behavioral Scientist, and Public Health Advisor. The group developed a framework of indicators, which Battelle refined and then used as the basis for its evaluation questions for a survey of **DCPs**. The group re-convened twice before and once after the survey pilot test.

The framework itself is attached as Appendix A. Its main components, discussed in greater detail at the end of this chapter, are (1) capacity building and infrastructure development, (2) surveillance and use of data, (3) health systems change, and (4) community development. Our model for the interaction of these components is presented in Figure 1.1.

In the model, the infrastructure and core capacity of state **DCPs** produces three types of program outputs:

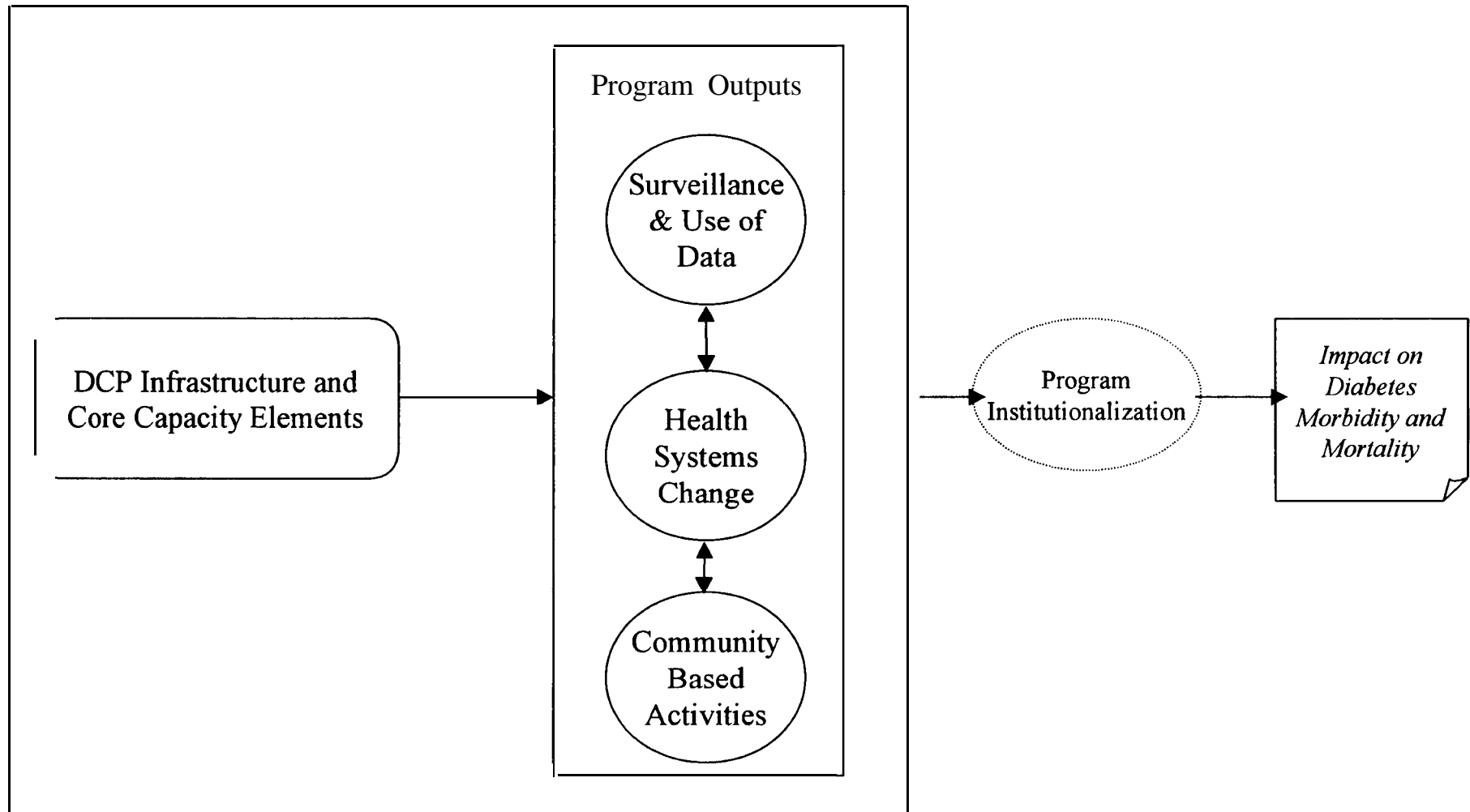
- The DCP's infrastructure and core capacity supports access to and utilization of surveillance data.
- The DCP's infrastructure and core capacity supports development of programmatic activities in the area of health systems change.
- The DCP's infrastructure and core capacity supports programmatic activities in the area of community development.

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<sup>1</sup> Hare, ML, JC Hersey, AE Roussel, MO Butler. *Evaluation of State-Based Diabetes Control Cooperative Agreement Programs: Feasibility of Approaches*. Report to CDC, DDT and OPPE (Contract 200-88-0642, Phase II) from Battelle-CPHRE, September 1995.

See also: LA Anderson, Bruner, LA, and Satterfield, D. *Diabetes Control Programs: New Directions in The Diabetes Educator*, Sep/Oct 1995, Vol121, No 5, p. 432 ff.

**Figure 1.1 Program Model**



Subject of this Study

These outputs, if effectively implemented, should lead to institutionalization of the State DCP with a subsequent reduction in diabetes morbidity and mortality.

### 1.3.2 Survey Pilot Test

The survey was pilot tested in late July and early August 1996 in three states.<sup>1</sup> The purpose of the pilot test was to (1) determine whether the survey questions were understandable, (2) assess the respondent burden, and (3) determine if the survey yielded the desired data. The pilot test states represented different demographics, amount of time as a DCP, and formal experience with managed care environments.

The strength of the survey instrument proved to be its ability to capture data across **DCPs** in a convenient format. Based on such a limited test we could only anticipate the overall utility of the instrument. We anticipated that it would yield good data concerning infrastructure and core capacity elements. In this way, we hoped to be able to make inferences concerning the relationship of infrastructure elements to programmatic elements. We also used respondent feedback to improve the wording of specific survey items.

### 1.3.3 Implementation of the Survey

Data collection began in April 1997 after receiving clearance from the Office of Management and Budget to field the survey. Before data collection began, the Project Task Leader met with DCP coordinators at the Division of Diabetes Translation (DDT) annual meeting in San Diego, California to inform them of the study purpose and methods. While we requested that states return the survey within three weeks, we actually accepted surveys for three months. The survey was sent in the form of a mailed self-administered questionnaire (SAQ).

The survey was mailed as an attractive booklet to the DCP Coordinator (Director in states which have a full-time DCP Director instead of a Coordinator) at each of the 42 state-based Diabetes Control Cooperative Agreement programs funded since late 1994.<sup>2</sup> The sampling frame for DCP

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<sup>1</sup> Hare, ML, MO Butler, C Betts. "Interim Report on Pilot Test of A Diabetes Evaluation Strategy Survey Instrument" to CDC, DDT and OPPE (Contract 200-93-0626, Task 06) from **Battelle-CPHRE**, September 1996.

<sup>2</sup> The **survey instrument** is attached as **Appendix B**.

Coordinator/Directors consisted of the entire universe of persons with such positions. A census was completed for this population, and no sampling procedures were utilized.

Battelle used intensive follow-up procedures. With such a small census, and so much variety among programs, our goal was a 100 percent response rate, something we did achieve with the cooperation of the respondents and their supervisors. Although our pilot test demonstrated that the survey should take about two hours to complete, in states where new staff had come on board during the present funding period, not all these staff had easy access to someone with an institutional memory to provide assistance in filling out the survey questions. These respondents needed to use program records or obtain information from someone presently in another position. The states that participated in the study are presented in Table 1-1.

**Table 1-1: States That Participated in the Survey of DCP Infrastructure and Activities**

Alabama	Maryland	Oklahoma
Alaska	Massachusetts	Oregon
Arizona	Michigan	Pennsylvania
California	Minnesota	Rhode Island
Colorado	Mississippi	South Carolina
Connecticut	Missouri	South Dakota
Georgia	Montana	Tennessee
Hawaii	Nebraska	Texas
Idaho	New Hampshire	Utah
Illinois	New Jersey	Virginia
Indiana	New Mexico	Washington
Kansas	New York	West Virginia
Kentucky	North Carolina	Wisconsin
Maine	Ohio	Wyoming

**One week after** Battelle sent the surveys to the **DCPs**, we telephoned each program to offer assistance. Most programs, except for those with new staff, were comfortable with the survey. **Beginning**

three weeks after mailing the survey, we maintained regular telephone, fax, and mail contact with each program that did not meet the original due date until all surveys were returned. Thank you letters were mailed to each participating DCP, as well.

## 1.4 Data Management and Data Analysis

Data management and data analysis procedures were used **that** were consistent **with** the descriptive nature of **this** survey. Data were quantified where appropriate, or open-ended responses were entered verbatim into a database. Frequencies were run for most closed-ended items, and bivariate analyses for a selected few indicators. We also performed content analyses comparing the data with features **that** were derived **from** the framework of indicators in Appendix A.

### 1.4.1 Data Management

Upon receipt, each survey was given an identifier and logged in on a checklist. The project Task Leader and the Study Manager **then** began the process of editing each survey. We verified **that** closed-ended questions were consistent **with** open-ended questions (e.g., **that** respondents did not check “no” and **then** give examples of a “yes” response) and made rules for inputting interesting comments that were not consistent **with** the questions posed. For example, when respondents wrote of plans for meeting strategic planning objectives, we created a field for “pending.” We kept track of all editing decisions on “edit logs” and made a consistent list of abbreviations. At times, when we needed more information to understand a response, we telephoned the DCP **to** discuss the problem.

Next, **Battelle** staff created a coding scheme based on repetitive patterns of response. Coding was based on a content analysis of twenty (47 percent) of the surveys and was supplemented by an analysis of unique responses as they occurred in the remaining surveys. Codes were also developed for closed items that did not present enough choices for the respondent (e.g., unanticipated staff members or data sources) or for responses in fields marked “other.” These codes were then entered into a *Microsoft* Access database. For detailed open-ended questions, staff entered verbatim text into the database. We verified 100 percent of the closed-ended (checklist or yes/no responses) and coded questions, and 10 percent of **the** text entry, by comparing the survey booklets with the entered text. It was found that **the** text entry was 100 percent accurate, so no further formal verification was done for these items. However, we did return to the survey

booklets frequently in writing about responses to open-ended questions, since it was sometimes necessary to abbreviate responses so they could fit into the database text fields.

#### 1.4.2 **Data Analysis**

This survey contains a great many open-ended questions necessitating a qualitative approach to analysis. At the same time, we have utilized descriptive statistics wherever appropriate. We also use content analysis to gain an understanding of lessons learned, obstacles, and how barriers are overcome in each of the programmatic areas. In addition, we use narrative to describe specific programmatic efforts, and we will present brief profiles to illustrate specific states' activities in the areas of (1) partnership building, (2) strategic planning, (3) surveillance, and (4) health systems change.

*Statistical analyses* describe the overall survey response and describe item-specific responses. We also conducted an analysis on the relationships between particular infrastructure elements and programmatic activities. This was based in part on bivariate analyses linking data on the presence or absence of key staff with evidence of selected programmatic efforts and activities. However, perhaps because of our small sample size, these analyses did not provide sufficient information for a quantitative assessment of the relationship between specific Diabetes Control Program infrastructure elements and the ability to carry out activities in select areas. Frequencies of key indicators demonstrating the degree to which **DCPs** are engaging in activities of interest have been developed.

*Content analysis* allows for a focused description when using qualitative data. An initial step in analysis is to develop a series of features to describe each of the four main components used in our survey of **DCPs** - infrastructure and core capacity, surveillance and use of data, health systems change, and community-based programs. Each component is discussed in the remainder of this section, along with the features used to guide the analysis.

**Infrastructure and Core Capacity Elements** - During the process of data analysis, we limited infrastructure elements to resources needed to implement a State DCP- human, financial, and in-kind contributions - and the organizational structure in which the DCP operates. Core capacity elements include partnership building through advisory structures and strategic planning; they extend infrastructure so that programmatic efforts can be carried out.

The analysis features for this component are:

- The DCP is able to utilize varied staff in areas that include but are not limited to program management, epidemiology, and other staff with expertise in affecting the health system.

- The DCP is able to leverage resources (human, material, and financial) from a variety of sources.
- The DCP is able to build partnerships within the state health department, with other state agencies, and elsewhere in the state.
- The DCP has an active and inclusive policy advisory body.
- The DCP has provided input into a strategic plan for diabetes that is used and can be evaluated.

Surveillance and Use of Data - At a minimum, state **DCPs** must be able to obtain, analyze, and use data to define and monitor the burden of diabetes. Our survey was mainly concerned with data sources available to **DCPs** and with barriers to data access. Use of surveillance and other data should be linked to program goals and objectives, as well. Therefore, we also sought evidence of dissemination of data and use for program planning and evaluation.

The analysis features are:

- The DCP utilizes the diabetes module of the Behavioral Risk Factor Surveillance System (**BRFSS**), and other key BRFSS questions, to track diabetes morbidity and evidence of care.
- The DCP undertakes a method to enhance the reach of the BRFSS, if appropriate to the State.
- **The** DCP is able to use additional data sources.
- The DCP disseminates data to a variety of audiences.

Health Systems Change - Coordinating the overall efforts of the health system to reduce the burden of diabetes is an important part of the work of state **DCPs**. We were particularly interested in whether there is evidence that the partnerships **DCPs** establish with other agencies and organizations do, indeed, extend programmatic reach to the states' diabetic populations. The kinds of data we used include brief descriptions of activities to extend access to education, resources, or care and to improve quality of care through education or dissemination of guidelines and standards.

The analysis features are:

- The DCP is knowledgeable about the present health system in the state.
- The DCP alone, or in partnership, has expanded its interactions with Medicaid, **MCOs**, or other key players in the health system.

- The DCP and its partners have taken steps to improve access and delivery of services for patients.
- The DCP works with its partners to influence legislation to assure that the needs of people with diabetes are served.
- The DCP works with its partners to disseminate standards and guidelines for care and to improve professional education.

**Efforts and Activities in Health Communications and Community-Based Activities** - Initially, a brief series of survey items concerning health communications was enfolded into the portion of the questionnaire that deals with core capacity. In the past year, CDC has been increasing the technical support that it gives to **DCPs** to implement health communications activities. Therefore, the data we received, though not comprehensive, indicated a greater move towards incorporating such efforts into the overall programmatic functions of the DCP than we had originally anticipated. **DCPs** may implement state-wide or community-based health communications activities, or both.

Our section on community-based activities was not meant to be as comprehensive as most of the other survey sections. Most programs report on these activities thoroughly in their progress reports, and out of respect to the issue of respondent burden we only sought information on numbers of educational and demonstration activities and on major barriers overcome.

The analysis features are:

- The DCP undertakes activities in the area of health communications.
- The DCP builds the capacity of communities to use data, prioritize needs, and plan interventions for the health goals of the community.
- The DCP identifies barriers at the community level and seeks to address them.

## **1.5 Organization of the Report**

This report is organized around the features just presented in Section 1.4. Findings regarding infrastructure are discussed in Chapter 2.0. Findings concerning the core capacity areas of partnership building through advisory groups and strategic planning are presented in Chapter 3.0. Surveillance and use of data are discussed in Chapter 4.0. Health systems change activities are discussed in Chapter 5.0, where findings regarding health communication and community-based activities are also presented.

Finally, in Chapter 6.0, we summarize the strengths and weaknesses of **the DCPs** and go on to suggest a long-term evaluation strategy based on strategic planning. Profiles of five **DCPs** - California, Washington, Utah, Texas, and Rhode Island - are integrated into the body of the report in order to illustrate particular programmatic successes. The document also contains three appendices. These are (1) the framework of indicators for evaluation questions (Appendix A), (2) the study instrument (Appendix B), and (3) a special report concerning managed care (Appendix C).'

## **2.0 Findings: Infrastructure Elements**

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## 2.0 Findings: Infrastructure Elements

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In this chapter, we present our findings concerning the basic infrastructure of diabetes control programs (**DCPs**). We look at staffing patterns, resources, and the organizational relationships of the **DCP** within the State Health Department and with other state agencies.

### 2.1 Staffing Patterns

The first basic infrastructure element that we examine in this chapter is summarized by the following feature:

- *The DCP is able to utilize varied **staff** in areas that include but are not limited to program management, epidemiology, and other **staff with** expertise in **affecting** the health system.*

In this discussion we look at staff from three perspectives. They are (1) the presence of someone “in charge” and the continuity of that person, (2) the presence of an epidemiologic or surveillance function, and (3) the presence of other staff who bring specific program-related skills to the program.

#### 2.1.1 Leadership of the Program

One way to characterize program management for the **DCPs** is to look at “leadership.” A DCP may be headed by a program director or a program coordinator. In addition, there may be a program director for the DCP who is also responsible for several other programs. One of the questions we sought to answer about staffing and internal infrastructure is whether or not the **DCPs** have had continuous leadership since July 1994 (the beginning of the most recent CDC Cooperative Agreement funding cycle). A criterion for “continuous leadership” was whether or not the DCP had a DCP-only program director or a program coordinator for 33 months or more. We also collected data on the presence or absence of a program director who was shared with other programs during this time period. We chose 33 months because this was nearly equal to the three years since the beginning of the latest funding cycle, minus three months to account for the fact that the questionnaires were being filled out in May 1997 (two months prior

to the actual three-year mark) and that at least the first month of the funding period may have been used to recruit for the positions.

Table 2-1 summarizes our discussion on program leadership.

Table 2-1: Program Leadership

Position Type	Frequency of Position Type Across states	Percent of states with this Position Type	Frequency that Position Type is Dedicated to DCP	Frequency that Position Type is Shared with other Programs
Program Director	31	74%	8	22*
Program Coordinator	28	67%	27	1

\* There is missing data for one program.

Program **Director**. Thirty-one states (74 percent) reported having a program director with at **least some** responsibilities for their **DCPs**. Of the 31 states, 19 of the director positions have been filled for more than or equal to 33 months (i.e., they have been “continuously filled” as we have defined it). Thus, 61 percent of the state **DCPs** have had continuous leadership in the form of a program director, many with leadership reaching back into previous funding cycles. On the other hand, 11 of the state DCP program director positions have been filled for less than 33 months, with a range of one to 27 and a mean of 13 months.

A program director can be either (1) a staff member of the State Health Department responsible for several programs, usually within a Division or Branch for Chronic Diseases, or (2) a DCP program director, responsible only for that program. Effective leadership requires the presence of someone who can focus completely on diabetes issues and is not pulled by the demands of several different chronic disease or adult health programs. Only eight states have a full-time dedicated DCP program director; five of those have been with the program for 33 months or more. One of these eight states has both a **DCP-only** program director and a program coordinator. However, that is one of two states that have “enhanced” **DCPs**. Enhanced **DCPs** received additional funding to carry out innovative programs with extensive reach.

**Program Coordinator.** The program coordinator is the person in charge of the DCP. There are 28 program coordinator positions (67 percent of the states) across all of the DCPs, and 67 percent of the states reported having this position on their DCP staffs. Of these 28 coordinator positions, only eight have been filled more than or equal to 33 months. Thus, 28 percent of the state DCPs have had continuous leadership in the form of a program coordinator for at least three years, and in some cases, far longer. Twenty of the positions have been filled less than 33 months, with a range from one to 29 months and the mean approximately 16 months. However, five of these 20 coordinator positions have been filled for two years or more. One of the program coordinators is shared with another program; all the rest are dedicated to the DCP.

Seven DCPs had neither a program coordinator nor a “hands on” (dedicated) program director at the time of the survey. We had hoped to be able to obtain further data on positions that had been filled intermittently. This proved confusing for respondents, and we have determined that such information is unreliable. We know from conversations with some programs that there have been shifts in leadership, sometimes leading to discontinuities in institutional memory and lapses in activities. Therefore, a major concern is that programs have not had continuous leadership, which delays the implementation of programmatic functions.

### **2.1.2 Epidemiologic and Surveillance Staff**

Another priority for characterizing internal infrastructure and staffing patterns is the presence of epidemiologists affiliated with the DCPs. Having an epidemiologist assigned to the DCP would make it easier for the program to monitor diabetes in its state and to use data for program planning and decision-making. Our data concerning epidemiologic and surveillance staff are presented in Table 2-2.

Nineteen of the 42 state DCPs (45 percent) have at least one epidemiologist position affiliated with their program. Two states have two epidemiologists, so that there are 21 epidemiologist positions across all of the DCPs. However, the epidemiologists have varying levels of commitment to the DCPs. We found that only eight of the epidemiologists are dedicated to the DCP and available full-time. Another one is less than full-time but is dedicated to the DCP only. Only two epidemiologists were with the DCP when this funding cycle began. Three states showed that the epidemiologist position is presently open. In a few states, more than one epidemiologist is available to the DCP on a part-time basis. For the most part, then, the epidemiologist is a shared position.

Table 2-2: Epidemiologic **and** Surveillance Support

<b>Position</b>	<b>Frequency (%) of states with position</b>	<b># of Positions</b>	<b>DCP only</b>	<b>Shared</b>
Epidemiologist	19 (45%)	21	9	12
Other Surveillance*	15 (36)%	16	8	7
Neither	12 (29%)	0	0	0

\* Four **states** have both **epidemiological and surveillance support**

**Surveillance staff.** Fifteen or **36** percent of the **DCPs** utilize surveillance staff other than an epidemiologist. Four states have both epidemiologic and other surveillance staff available for the DCP. On the other hand, 12 **DCPs** are without the support of an epidemiologist or other surveillance staff. The question of whether or not staffing patterns are related to the use of surveillance and health data is explored in Chapter 4.0, Surveillance and Use of Data.

### 2.1.3 Other Program Staff

Seven states (17 percent) have a **Public Health Advisor (PHA)**. One DCP did not complete all survey items relevant to this position; for the other six, the PHA is dedicated to the DCP at full-time. **PHAs** are CDC employees assigned to states and may have any number of roles to advise and support the program. One of the **PHAs** is assigned to a DCP with only one other staff, a ‘hands on” director, where a state hiring freeze has prevented filling two vacant positions for the program. The other **PHAs** are located in states with more robust DCP staffing patterns.

The category of Program **or Field Consultant designates** a state or DCP employee who supports the DCP in a variety of roles, such as providing technical assistance to programs or projects within the state. Some **DCPs have staff-level consultants who work with the program on a full-time basis**. A follow-up call to a DCP that used this designation for someone available to the program for a very limited number of hours revealed that the designation was also used for people within the State Health Department, but outside of the DCP, who provide consultation to the DCP. Ten **DCPs** (24%) reported a staff member in

this position category. Most of these positions are filled at half-time or more, with two states having two nearly full-time program/field consultants each.

**Health Education, Community Outreach, and Program Services.** A number of people with varied credentials provide specific services to the DCP or to the communities the DCP serves. The reliance of programs on such people, hired at the state level and paid with funds from the state, the DCP or both is extremely variable. Some **DCPs** have several nurse-consultants or diabetes educators available as paid staff, while others rely solely on a program coordinator and part-time epidemiological or surveillance staff. Table 2-3 presents data on the number of states that employ persons in the positions of communication or media specialist, certified diabetes educator (CDE), clinical nurse specialist (CNS) /program nurse, nutritionist, or health educator across the 42 **DCPs**. Respondents were asked to choose the title that best describes each staff member in cases where more than one title would be possible (e.g., nutritionist who is also a CDE, a health educator who is also a communication specialist).

**Table 2-3: State-Level DCP Staff Members for Health Education, Community Outreach, and Program Services\***

<b>Position</b>	<b>Frequency of states with Position</b>	<b>Frequency of Position Across States</b>	<b># Full-Time</b>	<b># DCP only (full or part time)</b>	<b># Shared</b>
<b>CNS/ Program Nurse</b>	15 (36%)	24	17	16	6
CDE	12 (29%)	16	5	9 **	7
Health Educator	12 (29%)	14	9	8	4
Nutritionist	6 (14%)	6	2	4	2
<b>Commu- nication or Media Specialist</b>	3 (7%)	3	1	1	1

\* Missing values are not included.

\*\* Some **DCPs** have both dedicated and shared staff for the same position category.

Looking at staffing patterns across all states, it is apparent that the staffing of **DCPs** is quite thin. There is no DCP staff category, outside of program coordinator, that is seen in half or more of all states. While small states tend to have small staffs, being a DCP in a populous state does not guarantee robust staffing. A large state that receives a great deal of funds from the state government has a very large **staff** - 13 staff members (11 of whom are full-time), the highest number among the **DCPs**. Most other large states do not have this level of support. Four **DCPs** have only two staff - and these are not all small states. When we calculated the mean and the median number of staff per DCP, the result was five for both mean and median. However, this should be read very conservatively, because so many programs rely on **part-time** staff. We did not see evidence of specific categories of staff with particular health systems expertise. We are aware that for some **DCPs**, these skills are integrated into those of program management or other **staff**.

Sometimes states look for creative solutions to lack of staff. For one DCP, all positions are subcontracted. (A Program Director, shared with other branches in Chronic Disease, is a state employee and available to the DCP on a part-time basis). Since becoming one of **CDC's** Diabetes Control Programs in 1994, this state has subcontracted all of its other positions. The full-time Coordinator works for the DCP under a subcontract with the state's affiliate of the American Diabetes Association (ADA). The other positions (epidemiologist, outreach director, CDE, Program Nurse, and evaluator) are subcontracted to universities at full-time **equivalencies (FTEs)** ranging from 0.13 to **0.35**. During a phone conversation with the Program Coordinator, we were told that this strategy helped the program to avoid problems with a state hiring freeze. This is the only instance we found of completely staffing the DCP through a subcontracting mechanism.

## 2.2 Resources

- ***The DCP is able to leverage resources (human, material, and financial) from a variety of sources.***

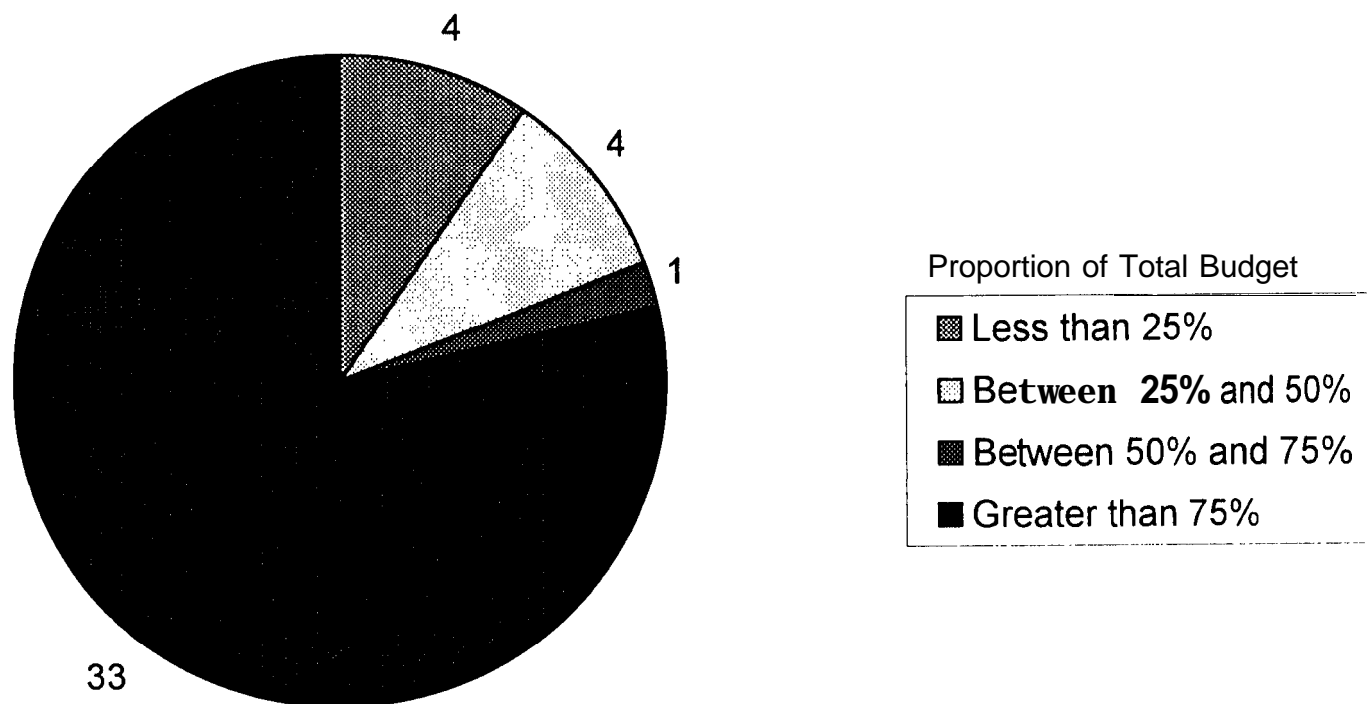
In addition to the Cooperative Agreement, from which all 42 programs in our survey receive funding, we wanted to know about other sources of funding for the state **DCPs**, as well as the proportionate contributions these sources were making to the total budgets. We asked the respondents to report whether they received money from three broad categories of sources: federal funding other than the CDC Cooperative agreement; state prevention block grants and other state funding; and "other." The

findings regarding the frequency which funds other than the CDC cooperative agreement contribute to the DCPs for fiscal years 1995 and 1996 are displayed in Table 2-4 below. Figures 2-1 and 2-2 present this information in greater detail, breaking it down by the proportion which particular funding sources contribute to programs' total budgets.

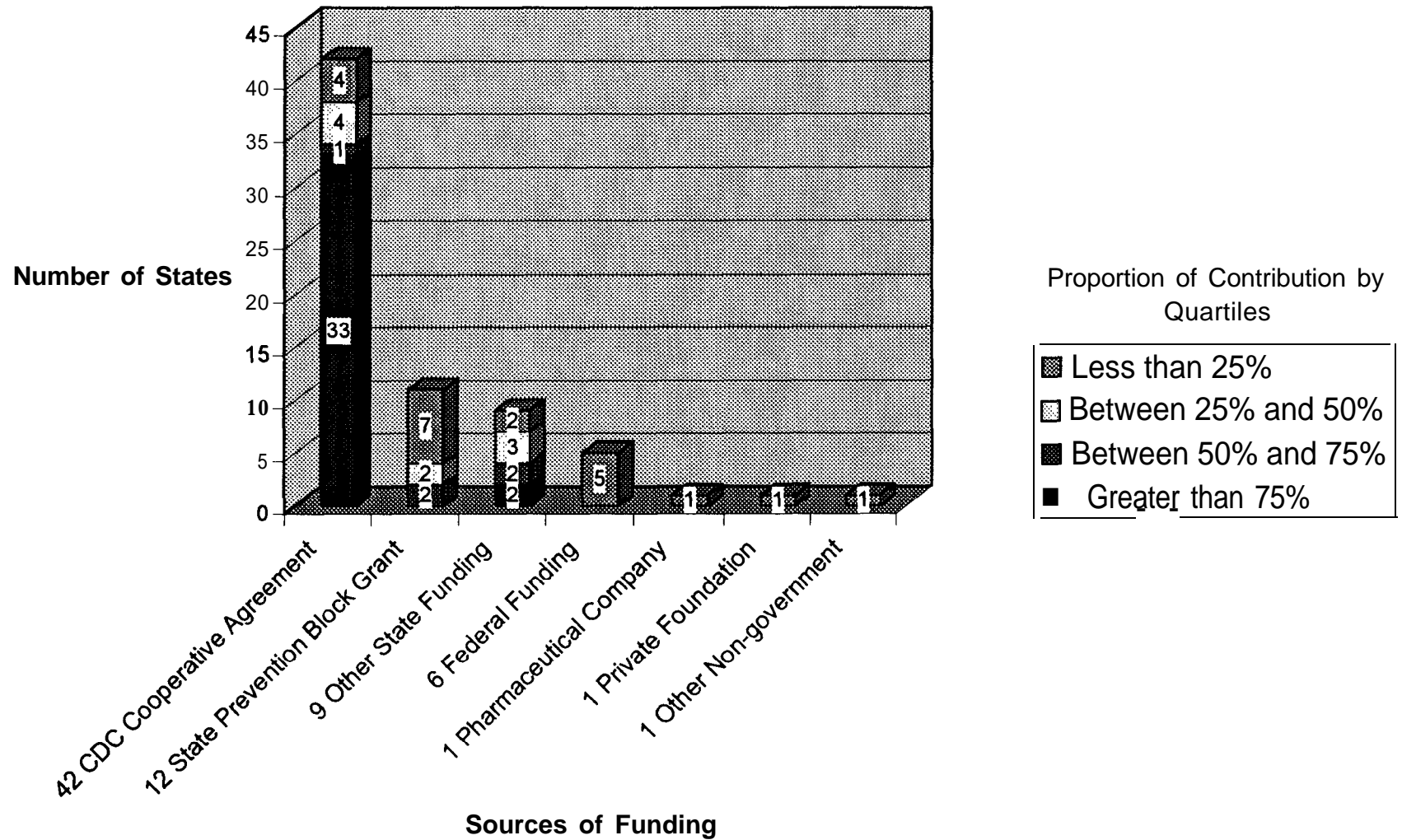
**Table 2-4: Sources of Funding Other Than The CDC Cooperative Agreement to DCP Budgets**

<b>Source of Funding</b>	<b>Frequency (%) of States with this Source of Funding</b>
Federal Funding (other than CDC Cooperative Agreement)	6 (14%)
State Prevention Block Grant	12 (29%)
Other State Funding	9 (21%)
Pharmaceutical company(s)	1 (2%)
Private Foundation	1 (2%)
Other non-government	1 (2%)

**Figure 2.1**  
**CDC Cooperative Agreement Funding**  
**The Proportional Contribution to FY 1996 Budgets by Quartiles and the Number**  
**of States Reporting for each Quartile**  
**N=42**



**Figure 2.2 Sources of Funding by Number of States and by the Proportion of Sources' Contributions to Overall DCP Budgets**



\* Two states did not provide information on the proportionate contribution of these sources to their programs.

About half of the state **DCPs** (**n=22**) reported CDC Cooperative Agreements as their sole source of funding. The most common source of non-CDC funding was the state prevention block grant (**n= 12**), and nine states reported other types of state funding. Six states reported receiving funds from federal sources other than their CDC Cooperative Agreement. While some states reported two or more funding sources, most did not. Four states reported “other federal funding” as the only additional source, and 13 states reported a state funding source as the sole additional source of funding. On the other hand, two states reported having all categories as funding sources.

The general pattern is that the **DCPs** relied heavily on Cooperative Agreements for the bulk of their program funding in **FYs** 1995 and 1996. We see that the majority of state **DCPs** (33 or 79 percent) receive between 75 percent and 100 percent funding from Cooperative Agreements for both FY 1995 and 1996. At the same time, other federal funding sources do not contribute much to the budgets of **DCPs** (less than 25 percent as a proportion of total budget for five of six of the **DCPs** reporting that source). The contribution of state funding is more substantial than other federal funding, but it still tends to be in the lower proportion quartiles. State prevention block grants consistently contribute less than 25 percent to the DCP budgets, while the contribution of other state funding tends to vary slightly more.

Other funding sources were reported by the state **DCPs** in addition to the four discussed above, including pharmaceutical companies, private foundations, and “other **non-governmental**.” However, these seem to be unique cases, and the contributions to DCP budgets were small in comparison to that made by public sources. Still, the ability to leverage these funds probably shows an ability to work outside of usual channels, a necessary skill in a changeable health systems environment.

### 2.2.1 In-Kind Contributions

The state **DCPs** were asked whether other organizations or agencies have donated “in-kind” support to the programs, such as services, equipment, or meeting space. Thirty-two states (76 percent) reported they had received in-kind support, and nine (21 percent) reported they had not. One state reported that it was in the process of negotiating in-kind support, but had not received the support at the time of the survey.

We also asked the state **DCPs** to list the types of in-kind support they had received and to indicate which programs, agencies, or organizations had donated the support. The 32 states that indicated they had received in-kind support provided 116 specific examples. We reviewed the responses and grouped both the kinds of support and the donors into limited sets of categories, as shown in Tables **2-5a** and **2-5b**.

The most frequently cited type of support is “logistical,” which includes meeting or conference space, materials, and services. The other most frequently cited types of support are “labor or service time,” “educational materials and dissemination,” and “miscellaneous equipment.”

**Table 2-5a: Types of In-Kind Support Received by the State DCPs**

<b>Type of In-Kind Support</b>	<b>Frequency across all states*</b>
Logistical support: meeting or conference space, materials, services	51
Labor or service time: staff, volunteer, or expert	21
Educational materials and dissemination	17
Miscellaneous equipment: glucometers, access to computers, mobile van, office space, food service, door prizes, etc.	16
Providing data or access to data	5
Leveraged funds	4
TV air time and PSA production	1
Other	1
<b>Total:</b>	116

\* DCPs could list multiple sources.

**Table 2-5b: Providers of In-Kind Support**

<b>Type of Organization or Agency</b>	<b>Frequency Across All Examples</b>	<b># Types of Support Donated</b>
Diabetes-related voluntary organizations	17	2
Pharmaceutical companies	17	4
Hospitals/medical centers	16	2
Public, private, and non-profit organizations - type unspecified by respondent	11	6
Specific non-profit organizations or associations that are not diabetes-related	10	4
Managed care organizations	8	3
State and local government agencies	8	4
Academic institutions	7	4
Other private health sector companies	6	4
Insurance companies	3	2
Local provider(s)	3	2
Peer review organizations	3	2
Retail companies	3	1
Medicaid	1	1
Other	3	2
<b>Total:</b>	116	43

The most frequently cited donors of in-kind support include the American Diabetes Association (ADA) and/or other diabetes organizations, pharmaceutical companies, hospitals/medical centers, a combination of public, private, and non-profit sector organizations, and non-profit organizations and associations. Other less frequently cited donors include managed care organizations, state and local government agencies, academic institutions, and other private, health sector companies. In addition, the range of types of support varied by the type of donating organization or agency. Some organization categories provided donations in as many as six different areas of support. Others focused their support in one area, mainly logistics - especially donating meeting space. The patterns of support were displayed in

Table 2-5b which compares the frequency at which a donor was cited with the number of types of support that donor provided.

With three-fourths of the **DCPs** leveraging in-kind support, this is an important way that the programs supplement their infrastructure. The leveraging of such support is important for another reason: it can build new partnerships or cement partnerships that are in place. Although not among the most frequently cited supporters, we believe that it is significant that **MCOs** were cited as frequently as state and local government agencies. This is because the relationship between **DCPs** and **MCOs** is still rather new in most states, while the relationship with state and local agencies is likely to be more longstanding (the DCP is part of a state agency). Still, among the most frequently cited supporters are the voluntary agencies concerned with diabetes (e.g., **state** affiliate of ADA or American Association of Diabetes Educators [AADE]). This is a crucial long-term relationship, since these groups are the main advocates for diabetes issues.

## 2.3 Organizational Structure

- ***The DCP is able to build partnerships within the State Health Department, with other state agencies, and elsewhere in the state.***

During our feasibility study, it was thought that the pattern of reporting, that is, the person to whom the DCP coordinator is responsible, could be a proxy for the level of influence the DCP has within the State Health Department. A majority of DCP coordinators (**25**, or **59** percent) report to a manager or director of disease control, prevention, or promotion. Three DCP Program Coordinators report to a DCP program director, and one said that the question of reporting was not applicable to the program. We believe that the pattern of reporting is likely to be shaped by factors within the State Health Department, rather than a factor inherent to the diabetes control program. This means that **DCPs** fit within an organizational structure that includes other chronic disease control, adult health, or, health promotion programs, and it is likely that the person in charge of the DCP reports to a superior in a manner similar to the person in charge of other programs. Since we had no way of exploring this belief further we could not use reporting relationships to be a good proxy for organizational influence.

### 2.3.1 Legislative Mandate

It is reasonable to believe that the presence of a legislative mandate for a diabetes control program would demonstrate greater commitment to diabetes issues on the part of state government than would lack of such a mandate. Seven states reported having a legislative mandate for their Diabetes Control Programs. Two of these seven states indicated that these mandates were established prior to the current Cooperative Agreement funding cycle (May 1983 and 1984). Three states received their mandates at the time of or after the beginning of the current Cooperative Agreement (July 1994, July 1996, January 1997).

We wanted to see whether there could be a relationship between the legislative mandate and funding from the state. A four-fold table comparing these variables is presented in Table 2-6.

**Table 2-6: Relationship Between Legislative Mandate and State Funding**

	<b>Legislative Mandate for Diabetes Control (Frequency / %)*</b>	<b>No Legislative Mandate for Diabetes Control (Frequency / %)**</b>	
<b>DCP Receives Funding from a State Source</b>	3 (60%)	12 (32%)	15
<b>DCP Does Not Receive Funding from a State Source</b>	2 (40%)	25 (68%)	27
<b>Total</b>	5	37	42

\* Percentage is based on the five states with a legislative mandate for diabetes control.

\*\* Percentage is based on the 37 states without a legislative mandate for **diabetes** control

Obviously, the number of cases is very small and no statistical tests showed any significant association between having a legislative mandate for diabetes control and receiving funds from the state.

### 2.3.2 Relationships within State Health Department and Across State Agencies

In this section, we examine the relationship of the DCP with other agencies, both within and outside of state government. These relationships reflect both the organizational structure of the DCP (e.g., the level at which the DCP reports within a Health Department) and the ability of the DCP to extend its

reach through building partnerships. In fact, this ability was implied by results showing that many **DCPs** leverage resources from outside of state agencies. It is in the building of partnerships that we also begin to look at the kinds of activities that **DCPs** participate in, influence, initiate, or implement.

**Collaboration Within State Health Department.** Thirty-three states reported that staff members of the DCP have served on committees of the State Health Department since July 1, 1994. We asked respondents about the State Health Department committees on which DCP staff members served, and grouped these committees into several categories. The types of committees and their frequencies of occurrence are listed in Table 2-7. While there are many types of committees, the **DCPs'** staff members tended to serve on some types more than others. The committees indicated most often were the ones related to Health Department administration and policy. This is not surprising, in light of the fact that a program coordinator would likely participate in some type of management or administrative committee across departments. The other most frequently indicated committees were those related to health promotion, working groups of various types, women's health, and disease surveillance. Committees concerned with managed care or Medicaid were cited very infrequently.

We asked which DCP staff members had served on State Health Department committees and in what capacity. The program director and coordinator positions were most often indicated as serving on the various committees (30 and 24, respectively), probably reflecting the fact that these were the most common full-time positions and also had the highest visibility within the state. Also frequently mentioned as serving on the State Health Department committees are the following positions:<sup>1</sup> CNS/Program Nurse, Epidemiologist, CDE, Surveillance, Health Educator, and Program/Field Consultant. The vast majority of staff members of the **DCPs** who served on State Health Department committees served as members, while several served as advisors, and a few, as officers. Considering the broad number of types of committees and initiatives named by respondents, it appears that **DCPs** are active players within their State Health Departments, but they are not displaying leadership roles.

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<sup>1</sup> In the order mentioned.

**Table 2-7: State Health Department Committee Membership Among DCP Staff**

State Health Department Committees	Frequency (%) across all states	State Health Department Committees	Frequency (%) across all states
Health Department administration and policy committees	32 (76%)	Conference Planning/Continuing Education	3 (7%)
Health promotion	13 (31%)	Managed Care or Medicaid	2 (5%)
Cardiovascular disease	4 (10%)	Disabilities prevention	2 (5%)
Working groups	11 (26%)	Community-based programs	1 (2%)
Disease surveillance	7 (17%)	Minority health	1 (2%)
Nursing	5 (12%)	Adult/senior health	1 (2%)
Other disease-specific committees	4 (10%)	Children's health	1 (2%)

Table 2-8 presents data on the programs, divisions, or branches within the State Health Department with which **DCPs** collaborate. More than half of all states have collaborated with either the Chronic Disease Division, Cardiovascular Health, or Minority Health agencies. We also see that between a quarter and half of all the states have collaborated with either the Health Department as a whole, a Medical Assistance Program (Medicaid Managed Care), Maternal and Child Health, Smoking, or Nursing agencies. Furthermore, we find that the **DCPs** listed other State Health Department programs not enumerated on the questionnaire, such as health statistics, nutrition, immunization, education, birth defects, elder health, health care quality, border health, communications, Tuberculosis, employee wellness, school health, refugee health, and rural health. Some of these designations overlap with those in Table 2-9, which deals with state agencies outside of the State Health Department.

**Table 2-8: State Health Department Programs, Branches, and Divisions  
with Which DCPs Collaborate**

<b>State Agencies within the Health Department with which DCPs Conducted Programs or Projects since 7/1/94</b>	<b>Frequency (%) Across all States</b>
Chronic Disease Division as a whole	34 (81 %)
Cardiovascular Health	33 (79 %)
Minority Health	24 (57 %)
Health Department as a whole	21 (50 %)
Medical Assistance Program (Medicaid Managed Care)	20 (48 %)
Maternal Child	17 (40 %)
Smoking	16 (38 %)
Nursing	15 (36 %)

**Table 2-9: Collaboration with Agencies Outside of the State Health Department**

<b>State Agencies Outside the Health Department with which DCPs Conducted Programs or Projects since 7/1/94</b>	<b>Frequency (%) of States</b>
Education	22 (52 %)
Legislature	18 (43 %)
Aging	16 (38 %)
Governor's office	14 (33 %)
Minority Issues	13 (31 %)
Social Services	9 (21 %)
Youth	8 (19 %)
Legal Department	5 (12 %)

**Collaboration with State Agencies Outside State Health Department.** In addition to participation in State Health Department committees or work with programs, branches and divisions within the State Health Department, we asked respondents to indicate whether they had conducted a program or project with certain state agencies within and outside of their respective State Health Departments since July 1994. The responses are summarized in Table 2-9 below. Only one non-State Health Department

state agency - education - appeared as a collaborating organization with more than half of the **DCPs**. Between a quarter and half of all the **DCPs** have collaborated with the legislature, the Governor's Office, or agencies for aging or minority issues. Again, the **DCPs** indicated they were collaborating with other non-State Health Department agencies not included in the questionnaire, but as before, the number of states collaborating with any of these agencies is low (12 percent or less). Examples include university, financial/administrative, Motor Vehicle, and Department of Corrections. One other factor to be considered is that some agencies that are part of the health department in one state may be located elsewhere in another. Examples include aging or minority issues. In such cases, we followed the respondent's designation and did not re-code the responses.

## **2.4 Discussion**

**DCPs** generally do not have large staffs. Rather they rely on a small number of people and categories of staff to carry out varied functions. Some have been without leadership for a portion of the present funding cycle and seven **DCPs** (about 17%) had no **DCP - only** program director or coordinator at the time of the survey. Even so, **DCPs** are well-represented in the State **Health** Department from the perspective of participation in State **Health** Department committees or collaboration with other programs, branches, or divisions. **DCPs** remain heavily dependent on the CDC Cooperative Agreement, but they do seem comfortable in leveraging in-kind support from a number of resources in their communities. This may be a result of a large number of efforts in partnership building outside of the state governmental structure. Such efforts will be **discussed** further in the next chapter.

### **3.0 Findings: Advisory Structures and Strategic Planning**

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### 3.0 Findings: Advisory Structures and Strategic Planning

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This chapter discusses core capacity from **the** perspective of (1) partnership building through the use of advisory groups, and (2) **the** presence or absence of a strategic plan. We continue to organize our chapters around features. As in chapter 2.0, whenever possible we use simple descriptive statistics to assemble the information discussed as part of each feature. At times, though, such quantification can be misleading. We often asked respondents for *examples* of activities, accomplishments, barriers, and lessons learned. We did this because one major purpose of this study is to develop information **that** will be useful to **DCPs** and to CDC in future programmatic efforts and in evaluating those efforts. Such information cannot be analyzed quantitatively because we have no idea how representative **the** examples given are of all possible examples. Instead, the information regarding accomplishments, barriers, and lessons learned was developed through content analysis of data in the surveys. For example, when we asked the respondents to list up to three examples of strategic planning objectives completed and, if relevant, barriers overcome, the content of **the** objectives was analyzed and grouped according to types of objectives, and then codes were assigned to each type or category. Although we rank the categories by the number of times cited, we request that the reader interpret these numbers with caution. Comments about barriers and lessons learned were entered into our database almost verbatim and are paraphrased, or occasionally quoted (but without attribution to the respondent) in the text.

#### 3.1 Advisory Structure

Advisory groups are generally considered to be necessary and important to many kinds of public health programs. They bring members of the community - both lay and professional - on board, and **they** can function as extenders of staff for such functions as developing strategic plans. Public health staff in government-funded positions are generally forbidden to lobby for specific legislative initiatives, even if they can advise on policy. Members of advisory groups, though, are often able to be more active than staff in the legislative arena. This is especially important for many **DCPs**, which may work hard on a policy only to see regulations added or subtracted that dilute the impact of its recommendations. Advisors are in a better position **than** state staff to address these concerns without being in conflict with **the** policies of their employer, the state. Finally, as the health care systems of states are changing, bringing new faces

to the table can serve as an educational strategy for the advisor - perhaps a clinician first learning about public health approaches. This could also be true for long-term members who may be working with new colleagues, such as administrators of health plans.

Butterfoss' addresses the benefits of coalition development, seeing such groups as "catalysts for community change." In our study, we have characterized coalitions as being the most independent of the types of advisory groups, but we believe that many of Dr. Butterfoss' comments are germane to the area of partnership building in general. Specifically, we cite the qualities of flexibility, of allowing for a "critical mass" of interested parties within partnership efforts, and of having a forum that "improves trust and communication among groups" that may be competitive with one another in other circumstances. Furthermore, as Battelle found in its 1994 case study, advisory groups can extend the reach of **DCPs**, especially when individuals work in subcommittees or task forces that take advantage of the member's area of expertise.

During our feasibility study, Battelle researchers examined progress and quarterly reports and other documents in an attempt to identify good indicators of effective committee work. Process measures, such as the number of meetings and the number of attendees, are often used, but the ways in which such measures can be shown ~~to~~ be meaningful for the promotion of programmatic processes and outcomes may be lacking. In this study, we decided to look at the make-up of the committee and its accomplishments as a way of assessing whether the advisory groups are active and able to accomplish meaningful tasks for the DCP.

In this section, we examine the qualities of the advisory structures that **DCPs** have developed. The specific feature we are looking at is:

■ ***The DCP has an active and inclusive advisory body.***

**The** characteristics for defining this feature include:

The advisory group has committees or task forces.

The advisory group brings on new members to reflect changing priorities.

The advisory group undertakes and completes particular tasks and demonstrates that it can learn from situations that prevent the completion of tasks.

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<sup>1</sup> **FD Butterfoss. "The ABCs of Developing and Nurturing Partnerships," presentation to CDC Diabetes Translation Conference, May, 1995, Denver CO.**

Before we discuss each of these characteristics, we present some baseline information concerning the structures of these groups, such as whether the advisory group is an independent coalition and to whom it reports.

Forty-one of 42 **DCPs** have, or use the support of, an advisory group. However, for two of these states, the advisory group was not active at the time of this study. One of the older **DCPs** has let all memberships lapse in its advisory group and is presently forming a new one. This is because DCP staff felt that the structure that had been operating in the past was best suited to the demands of the complications-specific approach of the previous funding cycle. Another DCP uses Work Groups to deal with specific issues rather than having a standing advisory group. The DCP Coordinator related that it takes between 0.5 and 1 .0 FTE to “make such a thing [advisory group] work.” At the time of the survey, the DCP was “between” Work Groups, although one had recently completed a study of the state’s insurance law. In the one state without any advisory group at all, there had been a Task Force appointed by the Governor. This Task Force lapsed in December 1994, and no new group took its place.

Table 3-1 presents basic information regarding the kinds of advisory structures with which **DCPs** work. We found that more than two-thirds of advisory groups are advisory councils and that more than half of the groups report directly to the DCP itself. We did not see any clear indication that a particular type of group follows a particular type of reporting pattern. For example, we had thought that a sign of the independence of the coalition format would be that it would report to itself or to some body outside of the state government. While this was true for one such coalition, we also have examples of an advisory council that reports to its own leadership and of coalitions that report to the DCP. One interesting finding is that, in the state that lacks any advisory group at all, the former Task Force reported to the Governor.

Table 3-1: Type of Advisory Group and Person or Agency to Which it Reports

Advisory Group Type	Frequency (%) Across All states	Agency or person to which the advisory group is responsible							
		Governor	Legislator	DCP	Health Officer	Board of Health	State Governor and DCP	The advisory group itself (coalition leadership)	Not Specified
Advisory Council	(67%) 8*	0	2	16	4	1	1	1	4
Coalition	(19%)	0	0	5	0	0	0	1	1
Work Group	4 (9%)	0	0	4	0	0	0	0	0
No longer has Advisory Group	1 (2%)	1	0	0	0	0	0	0	0

\* Information is missing for one coalition with regard to reporting mechanism.

We also looked for evidence that either changing the name of the advisory group or the person or agency to which it was responsible reflected a movement towards the public health paradigm of the 1994 cooperative agreement. This would be in contrast to the complications approach of the previous cooperative agreement. Four advisory councils and a steering committee were redesignated as coalitions, while one coalition became an advisory council. One DCP did not have a formal advisory group in the past, but it did have an *ad hoc* group of physician specialists who advised on particular matters; that state now has an advisory council. Two states chose to redesignate their advisory councils as work groups. Table 3-2 presents the differences in reporting structure (as specified in the group's by-laws) that accompanied changes in advisory group designation. Again, the findings are equivocal. Some DCPs that have had advisory councils in the past are moving towards coalitions, but where no advisory group existed before, the DCPs are generally creating advisory councils. The trend in reporting continues to be to the DCP.

**Table 3-2: Changes in Advisory Group Designation and Reporting Mechanism**

<b>Former Name</b>	<b>Agency or Person to Which Formerly Responsible</b>	<b>Present Name</b>	<b>Agency or Person to Which Now Responsible</b>
Steering Committee	DCP	Coalition	Coalition leadership
Advisory Council	Commissioner - Dept. Of Human Resources	Coalition	Not specified*
Advisory Council	Missing*	Coalition	Missing*
Advisory Council	DCP	Coalition	DCP
Coalition	DCP	Advisory Council	DCP
Advisory Council	Not applicable	Work Group	DCP
Advisory Council	Not applicable	Coalition	DCP
Advisory Council	DCP	Work Group	DCP
Task Force	Governor	No longer exists	Not applicable
Ad hoc advisory group	DCP	Advisory Council	DCP

\* Not specified or not applicable were choices offered to respondents. Missing means that this item was not completed by the respondent.

### 3.1.1 Presence of Standing Subcommittees or Task Forces

Thirty-five of the advisory groups contain either standing subcommittees or task forces, designate ad hoc subcommittees for particular tasks, or use some combination of these approaches. We asked the respondents to give us names of standing subcommittees or task forces. Table 3-3 presents the frequencies of such subgroups. Battelle developed the designations for the subgroups by coding the actual titles supplied by the DCP coordinators. Therefore, some states will have more than one of the same type of subcommittee or task force. For example, in one state there is a Communication subcommittee and an Education subcommittee - these both were designated as "Education - public, provider, consumer." Another state has three subcommittees, each of which deals with a different level of prevention (primary, secondary, tertiary),<sup>1</sup> and so the three were assigned to our prevention category. Because of these overlaps, we present only frequencies, not percentages.

Clearly, advisory groups are most involved with an educational function, followed by research issues. The third most active category is advocacy and legislation, followed closely by standards and guidelines. Interestingly, only one state has a Managed Care Work Group - something we would have expected to see more of by 1997. Unfortunately, our instrument was not refined enough to discover if some of the subcommittees dedicated to education were dealing with managed care or other health system issues. A few phone conversations with DCP coordinators indicate that this is so in at least some states. Also, information presented in Chapter 5.0 supports the possibility that this is the case, since many of the activities carried out by **DCPs** with their advisory groups and other partners deal with expanding coverage for patient education.

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<sup>1</sup> Primary Prevention, Prevention of Complications, and Intensive Management.

**Table 3-3: Frequency of Standing Subcommittees or Task Forces Across all DCP Advisory Groups**

<b>Type of Standiig Subcommittee or Task Force *</b>	<b>Frequency of Response</b>
Education: public, provider, and consumer	30
Surveillance, research, data collection / management	12
Advocacy and legislation	8
Standards and guidelines - development and implementation	7
Administration	6
Prevention	5
Access to care	4
Children's health and diabetes	3
Executive Committee	3
Reimbursement	3
Diabetes mobile clinic	2
Special populations (e.g., minority, underinsured, etc.)	2
Coalition building	1
Conference planning	1
Funding	1
Government relations	1
Industry advisory	1
Managed Care Work Group	1
"Other"	2

\*

A DCP may have cited more than one subcommittee or task force in any particular category.

### 3.1.2 Member Composition of Advisory Groups

Due to concerns about respondent burden, we did not ask DCP staff to tell us which agencies comprise the advisory bodies. We used proxy questions that got at composition by asking about changes in membership since mid-1994. In most cases, we were able to tell what kind of agency was represented when a respondent gave us the name of a new member organization, and we occasionally called a DCP to discuss this matter. Our questions were most useful for simply learning whether advisory groups were undergoing membership changes to better reflect the health systems paradigm.

These questions were targeted only to **DCPs** that had been funded during the previous funding cycle (i.e., not to programs that were new mid-1994). Twenty-five (59%) **DCPs** in the sample had received a cooperative agreement in the immediately prior funding cycle.<sup>1</sup> Nineteen of those states acquired new members in their advisory groups, but only six said that they had dropped some members. One reason for loss of members is that occasionally the sponsoring organizations cease to exist. One state, which is overhauling its advisory structure, has let all members lapse and is seeking a new group.

The kinds of members acquired are wide-ranging, with a concentration from professional organizations. Table **3-4** shows a breakdown of the types of member agencies reported; it is important to remember that these are not necessarily all of the new member organizations across all of the **DCPs**.

### 3.1.3 Evidence of Accomplishments

We asked the **DCPs** to tell us about the kinds of activities initiated, achievements accomplished, and barriers overcome when working with their advisory groups. The most common activities dealt with development and distribution of guidelines, followed by the development of goals and objectives for diabetes control. These are clearly advisory functions, but may not require as much involvement as lobbying or legislation efforts, which were not cited as often in response to this set of questions. There is some difference between the intensity of activity seen here and that noted later in the report, probably because we ask for accomplishments here but later probe for initiatives that the DCP may have merely influenced.

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<sup>1</sup> Any DCP that had been funded in an earlier - before 1989 - funding cycle, but not from 1989-1994 was counted as new.

**Table 3-4: Types of New Agencies and Members Added to Existing Advisory Groups**

<b>Member Category</b>	<b>Frequency of Representation*</b>
Professional associations (not specific to diabetes)	10
Clinic, medical center or hospital, unspecified health organization	9
Peer Review Organization, HCFA, Medicaid	8
Insurance companies and managed care organizations	7
Advocacy group (older adults, kidney foundation, visually impaired)	6
Professionals (dentist, pharmacists)	5
Educator	4
Other government agencies	4
Home health agency	3
Professional associations - diabetes-related	3
University or academic organization	2
<b>Unspecified</b> - new member or consumer	2
Indian Health Service	1
“Other”	4

\* Respondents cited multiple categories.

In the remainder of this section, we will present data on each category of accomplishment. It is critical that the reader note that we elicited up to three examples of activities accomplished by its advisory group from each DCP. We did not ask for an exhaustive list of accomplishments, so the frequencies should be read with caution, since we do not know how well the examples represent all possible examples. It should also be remembered that a DCP could cite more than one accomplishment that fell into the same category. **Beneath** each category are barriers and lessons learned as cited by respondents for each type of accomplishment. We do not rank these, since many are unique. On the other hand, many are concerned with issues of building consensus or lack of time and resources.

- **Develop or distribute standards or guidelines for care, screening, and education** - Nine examples

**Barriers** - Achieving consensus and “getting this size group together”

Competing agendas of individuals or health plans

Lack of time, either for DCP staff or stakeholders

Lack of clear and consistent national recommendations

Difficulties in working with Medicaid

Low response from physicians

Lack of a “mechanism to determine utilization” by providers

Lack of funds for publication

**Lessons** - Consensus from expected users of standards is necessary

Have a good facilitator

Leadership should be proactive

“If you want a product, you must make decisions, you can’t make everyone happy. ”

- **Develop goals and objectives for diabetes control** - Eight examples

**Barriers** - “Turf issues [which are] to be expected”

CDC cooperative agreement guidelines

Health department policies

**Lessons -** There is a need for buy-in

“The medical specialty approach is not best”

Core public health functions and *Healthy People 2000* are helpful for developing goals

“Be vigilant”

The process can be accomplished and it “is valuable”

■ **Patient education and health promotion activities - Six examples**

**Barriers-** Lack of time and money

The logistics of dealing with schedules and geography

Disappointment with low utilization

One program was so successful that 125 people were turned away

Lack of willingness on the part of clinic administrators proved to be problematic

It took “a lot of work to educate ‘gatekeepers’ on the importance of the project”

**Lessons -** One state said that those taking certified diabetes educator (CDE) exams had difficulty passing them, or meeting the 2,000 hour rule for obtaining certification

“Rural communities really need updating”

“Have public relations in place”

Have physicians provide professional education to other physicians

“Keep your eye on the goal, and maintain motivation and quality”

One particular example stands out. This was a state that wanted to implement an exercise physiology program using a “circuit-riding exercise physiologist.” The respondent said of this effort: “the thought was public health [but] when it became clinical it was not cost-effective.”

■ **Lobbying and diabetes legislation efforts - Six examples**

**Barriers-** Obtaining consensus and buy-in, both from within and outside of advisory groups  
Difficulty in getting information from **MCOs** and from the state’s regulator for insurance

The power of special interests and the insurance industry

Rules against lobbying by the DCP and some advisors

**Lessons-** Develop strong partnerships

The need for other organizations to be involved or “lead the charge”

Identify supporters early on

Obtain needed information

One state noted that members of the coalition formed a separate coalition in order to lobby.

■ **Data collection, analysis, and dissemination - Five examples**

**Barriers -** **The difficulty** of clarifying language for the non-technical respondent to an interview, especially in a state with a large population for whom English is not a first language

Obtaining a representative sample of people with diabetes

The length of the survey

Limited resources such as volunteers, time, and money

Approval by a state oversight body

“Territorialism”

Including the pharmaceutical industry in its project when the advisor from that industry did not attend advisory group meetings

***Lessons learned from the data -***

Patient knowledge about **HbA1c**, microalbumin, and foot examination is low

There is a need for standards and practice guidelines

***Lessons about data collection, use or dissemination -***

There is a need for patience, coordination, and early action

“Increased input **from** local educators resolved [problems with] the final system”

Producing a report for publication rather than one that just “sits on a shelf

The data -related project proved to be a “valuable means for enlisting buy-in”

· **Develop guide to diabetes resources and benefits -** Two examples

***Barrier-*** Deciding on the format of the guide and its target audience

“Issues over ownership”

***Lessons-*** Group effort and collaboration

A need for field testing and evaluation

· **Fund-raising and coalition building -** Two examples

***Barriers -*** Lack of support from the governor (**fund raising**)

“Turf and self-interest”

***Lesson -*** “Identify a champion and start again when the climate is better”

Many of the issues that surfaced in our data concerning accomplishments of advisory groups will be re-visited as we look more closely at activities and initiatives specific to the area of health system

change. In the meantime, Profile 3-1 (at the end of this chapter) provides a picture of a state that has used a coalition structure for its advisory group since late in the last funding cycle.

## 3.2 Strategic Planning

In developing the present study, Battelle and its advisors were concerned about the issue of strategic planning. Prior research, and the experience of some advisors, led us to wonder whether DCPs set goals and objectives in concert with others in the state health department, or with partnerships elsewhere in the state, and whether such planning is useful. A major question became, “Does the DCP have an active strategic plan or does it [the plan] just sit on a shelf?” We defined an active strategic plan as one with goals and measurable objectives that are used to guide the DCP. The feature, then, under analysis in this section is:

- *The DCP has **provided input into a strategic plan for diabetes that is used and can be evaluated.***

An effective strategic plan requires (1) a definition of the burden of diabetes in the population, **(2)** an understanding of health systems (structures, functions, and dynamics of change) supporting the delivery of preventive services to persons with diabetes, **(3)** a linkage to community norms and organizations affecting delivery of the program, (4) a process for monitoring and evaluating implementation of the strategic plan, and (5) a regular means to update the strategic plan to accommodate changes in the program or in the environment in which it operates. Unfortunately, the survey instrument does not collect information on **exactly** what is in the state strategic plans - a task that would have been too burdensome using a mailed self-administered questionnaire. Still, we can logically infer that a relationship exists between having an active strategic plan and an active program. This does not mean that DCPs that do not have current strategic plans are not engaging in programmatic activities. However, such DCPs may be limited when it comes to evaluating their programs. In this section we will discuss our results concerning strategic planning activities, and in Chapter 6.0 we will more fully discuss the relationship between strategic planning and evaluation.

In practice, we found several variations on strategic planning. These include DCPs with no evidence of a written plan other than the goals and objectives presented in their cooperative agreement applications, DCPs with their own strategic plans, and state strategic plans with a diabetes component. One variation that we had not counted on when we fielded the survey was the use of recommendations,

rather than objectives. Thus, in some cases we could not use a measure to determine if the plan was “active” ( i.e., completing objectives), because recommendations are meant to be ongoing.

### 3.2.1 Extent of Strategic **Planning**

A little over half of the **DCPs (n=24, 57 percent)** are located in states that currently have a completed strategic plan for diabetes. We differentiate between **DCPs** that have their own strategic plans and those that are located in states where diabetes is part of a statewide strategic plan. Thirteen **DCPs (30 percent)** write their own strategic plans and the same number are located in states that engage in strategic planning for diabetes at a level beyond the DCP. Of these, two states have both a DCP-level plan and a state-level plan. For the 13 states with state-level plans, three states have a strategic plan devoted entirely to diabetes and 10 include diabetes objectives in a state strategic plan. Three states told us about current strategic planning activities - two at the DCP level and one at the state level - and others may have been engaged in the process but did not volunteer the information. As seen in Table 3-5, the trend is towards strategic planning, with an increasing number of states completing the process beginning with 1995.

**Table 3-5: The Year in Which Strategic **Planning** Was Completed**

<b>Year</b>	<b>Number DCP-Level Strategic Plans Completed</b>	<b>Number State-Level Strategic Plans Completed</b>
1991	none	1
1992	none	1
1993	1	1
1994	1	1
1995	3	1
1996	2	4
1997	6	<b>3</b>

For strategic plans completed at the state level, we asked whether or not the DCP provided input into the strategic planning process, alone or with the advisory group. Table 3-6 summarizes the responses.

**Table 3-6: DCP and Advisory Group Input into State-Level Strategic Planning for Diabetes**

<b>DCP provided input into the development of the plan?</b>	<b>Advisory body provided input into development of the plan?</b>
YES 11 (85%)*	YES 6 (46%)
NO** 1 ( 8%)	NO** 6 (46%)

\* Numerator for all percentages is the 13 states with state-level strategic planning for diabetes.

\*\* There is one missing value.

There is one state for which no input was provided by either the DCP or its advisory group. This DCP was unable to answer any of our questions about the objectives in the plan.

### 3.2.2 Progress Towards Meeting the Objectives in Strategic Plans

Table 3-7a summarizes progress towards meeting objectives in DCP strategic plans, and Table 3-7b in state-level strategic plans. As noted in the tables, not all **DCPs** that said that they have strategic plans supplied information about objectives (in progress or completed). It appears that respondents for DCP-level plans were somewhat better able to supply information, perhaps showing a greater involvement with the plan than those who solely use state-level plans. Not surprisingly, more recent plans have fewer completed objectives than older plans, but the oldest plans seem to fall out of use. By and large, though, **DCPs** with strategic plans show evidence of using them. One confounding factor is three states that use “recommendations” and not objectives. Recommendations are meant to be ongoing; i.e., not to be completed.

**Table 3-7a: Progress Towards Meeting Objectives - DCP-Level Strategic Plans\***

<b>Year Plan Was Completed</b>	<b>Number of Objectives in Plan</b>	<b>Number of Objectives in Progress</b>	<b>Number of Objectives Completed</b>
1993	35	Missing	Missing
1994	05	00	05
1995	62	49	13
1995	27	05	09
1995	27	12	09
1996	05	02	03
1996	17	02	13
1997	28	04	09
1997	06	01	05
1997	Missing	Missing	Missing
1997	05	00	05
1997	18	00	18
1997	04	03	01

\*

As of May 1997

**Table 3-7b: Progress Towards Meeting Objectives - State-Level Strategic Plans\***

<b>Year Plan was Completed</b>	<b>Number of Objectives in Plan</b>	<b>Number of Objectives in Progress</b>	<b>Number of Objectives Completed</b>
Missing	Missing	Missing	Missing
1991	16	Missing	14
1992	37	26	12
1994	04	00	01
1995	05	01	05
1996	02	02	00
1996	Missing	Missing	Missing
1996	Missing	Missing	Missing
1996	01	00	01
1997	10	00	10
1997	Missing	01	00
1997	20	00	15
1997	04	00	04

\* One of 10 DCPs with state-level plan did not supply any information on year of completion or objectives.

**Objectives Accomplished - DCP-Level Strategic Plans.** Content analysis of answers to open-ended questions demonstrated that objectives fell into several overlapping categories. We present the most frequently cited category first (eight examples) and least frequently cited last (one example). While our question asked for information about “objectives completed” and solutions to barriers, we include some interesting examples of ongoing objectives that are being “addressed.”

■ **Education and awareness - Eight examples**

This category includes objectives to educate or raise awareness among providers, consumers and the general public on diabetes issues.

**Solutions to barriers-**     **Focus** work on the goal at hand when multiple agendas are present

Raise awareness through presentations to fellow employees at chronic disease meetings, local and regional meetings of diabetes educators

Solve cost and knowledge barriers in a media campaign by partnering with an existing health promotion campaign

■        **Research and surveillance activities** - Three examples

Objectives in this category are focused on data systems development, data collection and data analysis.

**Solutions to barriers -**     Partner with the state diabetes association and with the **office** of public health data in its state health department to decrease costs

■        **Health systems change and policy advocacy** - Three examples

Objectives are concerned with affecting the system for delivering diabetes care and services.

**Solutions to barriers -**     Obtain support from an insurance division

■        **Improvements in quality of, and access to, diabetes care and services** - Three examples

This category includes objectives concerned with the actual delivery of care and services.

**Barrier -**                         Contractual constraints at community health centers [type of constraint and solution not specified]

■        **Community services, mobilization and training** - Two examples

This category includes, but is not limited to, efforts to place diabetes workers in communities, as well as training for facilitators and other community mobilization activities.

**Solutions to barriers -**     Hire appropriate staff, such as professionals from minority groups

■        **Increased resources** - Two examples

We used this category when the purpose of the resources cut across many areas or when the purpose was not specified.

**Solutions to barriers -**     Partner with other state agencies  
Fund primary care clinics with state funds

•        **Partnership building** - One example which simply discussed the need to foster collaboration

**Objectives Attempted - DCP-Level Strategic Plans.** For the present survey to serve as a basis for future planning, assistance, and evaluation, it was necessary to learn something about objectives that were attempted but not completed. Therefore, we asked each DCP to describe as many as three objectives that were incomplete and problems that had been encountered where solutions may not yet be apparent, or where there was no solution. We saw a new category emerge, one having to do with improving specific health indicators. We again used content analysis for categorizing the examples and then paraphrased the information provided by respondents on barriers associated with each category. Also, it should be mentioned that not all states cited barriers; some simply said that the objective was in progress, and it was too soon for it to be completed.

■ **Education and awareness - Six examples**

**Barriers-** Lack of resources, such as time, money, or staff

■ **Improvements to quality of and access to diabetes care and services - Four examples**

**Barriers -** Lack of data or inaccessible data

■ **Health systems change and policy advocacy - Three examples**

**Barrier -** *State's* Medicaid program, though supportive of the “idea” behind the objective, was concerned about the cost of program for addressing the objective

■ **Improvements in specific health indicators - Two examples**

This category is concerned with the use of indicators that show a specific decrease in the burden of diabetes. Examples may include decreasing the prevalence of blindness or of undiagnosed diabetes.

**Barriers -** Inadequate state data sources

■ **Community services, mobilization, or training - Two examples**

**Barriers -** Lack of staff to identify key individuals in communities

■ **Research and surveillance activities - One example**

**Barrier-** DCP does not have epidemiologic support

**State-Level Plans: Objectives Completed.** Information on state-level plans is presented separately because there is a small difference in the number of times that categories of accomplishments are cited. Unfortunately, as seen in Table 3-7b, there is more missing data for state-level plans than for DCP-level plans. We use the same method as we have throughout this section of the chapter.

- **Education and awareness** - Six examples

**Solutions to barriers** - Partnering with providers of training  
 “The process must be ongoing and never ‘completed’”

- **Research and surveillance activities** - Two examples, both from the same state

**Solution to barrier** - Conduct focus groups in the community of interest

- **Community services, mobilization, and training** - The one state that cited an objective in this category did not volunteer any solutions to barriers

- **Improvements in specific health indicators** - One example

**Solution to barrier** - Through an intensive statewide effort to decrease the infant mortality rate, obstetricians and gynecologists became more aware of management of diabetes during pregnancy

- **Health systems change and policy advocacy** - The one state that cited an objective in this category did not volunteer any solutions to barriers

**Objectives Attempted - Statewide Strategic Plans.** Only five states gave specific information in this category (one simply said that all objectives are in progress), but those that did tended to cite more than one example, sometimes falling in the same categories Battelle used for coding. The first category was mentioned six times, and the others only once or twice.

- **Improvements in specific health indicators** - **Lack of education** or knowledge was cited by one state, and another was concerned with **time** and the demographics of its population, specifically age.

- **Improvements in quality of and access to diabetes care and services** - One state cited several barriers such as **provider unresponsiveness and ineffective self-management by patients**. A solution on the horizon is legislation that will allow insurance coverage of patient education. Another state simply cited **time** as a barrier in its effort to increase access through regional networks.

- **Education and awareness** - Primary care providers **do not refer** patients for education. Legislation is being passed to address this problem, presumably making it easier for providers to refer since they would know that the service is paid for.

- **Community services, mobilization, and training** - In the one state citing this objective, the respondent was concerned with an inability to provide the funds necessary for program implementation due to **restrictions on spending**. Both DCP- and state-level strategic planning emphasize educational activities, as well as data collection. Respondents were more likely to give examples of objectives concerning health systems change for DCP- level strategic plans than **state-level** plans. On the other hand, from the examples given, state-level plans seem to be more concerned with community-level activities and with tying objectives to specific health indicators than the DCP-level plans.

### 3.3 Discussion

This chapter focused on two areas of DCP capacity - the use of advisory groups and strategic planning. Both of these components should extend the reach of the programs. In most cases, there is evidence that advisory groups do extend the reach of the DCP through a variety of activities. DCP advisory groups seem to be most comfortable with activities that have an educational component, but this does not mean that the activities are not addressing health systems issues at the same time. In Chapter 5.0, we will see that it is likely that **DCPs** are combining efforts in education and health systems change.

We also saw evidence that **DCPs** are moving towards the use of strategic plans, but there are still a large number of **DCPs** without such plans. We did not see evidence of evaluation of strategic planning, except in those states that have adopted objectives that depend on indicator-based data. However, evaluation of the plans was not fully explored in the questionnaire. One interesting trend that may be emerging in strategic planning is the use of indicator-based data for measuring progress toward improvements in health. In the next chapter, we will examine how **DCPs** use surveillance data to monitor the burden of diabetes, and we will be able to make some tentative statements about the use of data for planning and decision-making.

Profile 3-2 describes a state with several strategic planning objectives in progress. It is also one with an active program, which suggests that these two aspects of the DCP are linked.

### Profile 3.1: Advisory Structure

We chose a state, **California**, with an interesting but not necessarily typical advisory structure for this profile. **That** is because we wanted to learn more about the use of free-standing coalitions and see if there may be lessons for other states. Before looking specifically at coalition activities, we will briefly look at infrastructure elements for this DCP.

California had a population of close to 30.9 million people in 1992. According to CDC data available for 1994, there were **1,054,127** adults in California (or 4.6 percent of the adult population) with diagnosed diabetes, and probably another 750,000 adults with undiagnosed diabetes in the state. CDC also estimated that the direct cost of diabetes to the state was \$13.7 billion in 1992.

The California Diabetes Control Program was established in the early 1980s. It has three full-time staff members - a Program Coordinator, an Epidemiologist, and a clerical staff member. As of the date of our survey, the Program Coordinator had been on board for less than two years, and the Epidemiologist, for only six months. Although the current Epidemiologist has been part of the DCP for such a short time, the program had a different Epidemiologist on staff for one year. At other times, the DCP has received epidemiological support from other Chronic Disease Branch staff. Other support from the Chronic Disease Branch has included about 0.05 full-time **equivalency** (FTE) from the Branch Director and 0.25 FTE from the Branch Chief. The California DCP received 100 percent of its funding from the CDC Cooperative Agreement for fiscal years 1995 and 1996.

California changed from a steering committee type of advisory structure to a coalition in October of 1993. A little more than a year later, its by-laws were changed such that the coalition became responsible to its own leadership, but with input from the DCP. The DCP and Coalition function as partners on various projects. The Coalition contains both standing and *ad hoc* subcommittees. The standing subcommittees include: Treatment Guidelines and Standards, Advocacy, Education, Evaluation, and Communication. Since the beginning of the latest CDC Cooperative Agreement (July 1, 1994), the California DCP Coalition has gained new members, including representation from one of the state's largest managed care plans. Meanwhile, the Coalition has not lost any members.

The California DCP provided examples of activities or initiatives accomplished with the Coalition since July 1, 1994, the barriers to achievement that were encountered, and lessons learned from the experience. The first example is the development of Basic Guidelines for Diabetes Care. In this example,

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the barriers encountered were the difficulties in achieving consensus due, at least in part, to the large number of health insurance plans in such a large state. The lessons learned from this achievement are the importance of proactive leadership and the need for clearly defined criteria for inclusion of a guideline item.

The second accomplishment is the development of a Diabetes Health Record, or the companion piece to the Guidelines. A lesson learned was the need for field testing and evaluation of the Record.

The third accomplishment is a patient care survey. In developing the survey, it was necessary to consider such issues as phrasing questions so they are understandable to the recipients of the survey and the difficulties of getting a representative sample of the different populations in the state. The survey was sent to people of diverse economic and ethnic backgrounds and to people with and without managed care coverage. After the survey was administered, the DCP validated the survey through chart abstractions for a subset of the sample. From this activity the California DCP learned both the extent and limits of reliability of the patient survey and medical records. The surveys and record abstraction showed that patient knowledge of **HbA1c** and micro-albumin are low and that provider charting of foot exams is also low.

The California Diabetes Coalition is a partner in a variety of advocacy activities in the areas of extending coverage and access, disseminating and promulgating guidelines, and increasing awareness of diabetes issues. The Basic Guidelines for Diabetes Care are particularly important to the establishment of standards and guidelines for physicians, other medical providers, diabetes educators, and managed care organizations, as well as related issues of coverage for medical services. The Basic Guidelines also serve to further the professional education of physicians and other health care workers.

The Diabetes Coalition predates most of the program staff, a staff that is small for such a large population. Yet, together, the California DCP with the Coalition demonstrate the kinds of public health leadership activities that can be undertaken, as well as barriers that are overcome in a large state.

### Profile 3.2: Strategic Planning and Programmatic Activities

This profile is of a state that presents evidence of having **both** an active strategic plan and an active program.

Utah, with a population of about 1.8 million people, had 43,086 adults, (3.7 percent of the adult population) with diagnosed diabetes in 1994. **Also**, according to CDC data, the direct and indirect costs of **this** disease to the state totaled \$504 million in 1992.

Established in 1980, the Utah DCP now has a staff that consists of a full-time Program Director, a full-time Program Nurse, a full-time Community Health Specialist for reimbursement issues, a full-time Health Educator, and full-time clerical support. Although a nutritionist is available for half-time, surveillance support is only available at 15 percent of an FTE. The DCP receives all its funds from the CDC cooperative agreement. It has leveraged in-kind support from a variety of organizations and individuals, such as a local ophthalmologist for meeting space, the state peer review organization (PRO), **the** state diabetes association, and media outlets.

The Advisory Council, or Board, was established “in the **1980s.**” It has several standing subcommittees or task forces **that** address such issues as professional, public and patient education, data and surveillance, and health systems.

One activity of the Board was **the** development of a strategic plan for diabetes in Utah. This plan was completed in 1995 and is currently being updated. The survey respondent advised that a lesson for strategic planning is to “get buy-in from key stakeholders.” Of **the** 27 objectives in the strategic plan, Utah has completed 12, with another nine in progress. Partnering with other organizations was cited as important to completing such objectives as a provider survey and a media campaign. A community mobilization needs assessment and intervention was also cited as completed. Barriers to completion of objectives include lack of staff and lack of time, as well as lack of follow-through by another agency.

The community mobilization objective is interesting in light of Utah’s activities **with** Diabetes. Today, other diabetes education, and local community-based demonstration projects. The latter involved partnering with the Indian Health Service.

The DCP is active in other areas as well. It conducted a few very small targeted surveys to supplement the BRFSS. It used results of questions on weight loss to guide the development of its media

campaign, used CVD risk factor data for Diabetes Today communities planning community interventions, and uses risk factor data for annual program planning “and as baseline for outcome objectives.”

Utah has also been active in health systems change and advocacy. The DCP has collected Medicaid utilization data and surveyed **MCOs**, but the impact of these activities was not yet assessed. The DCP supported legislation to improve portability of benefits and has conducted educational and **data-**gathering activities to expand coverage. It has “assisted the Medicare intermediary to develop a policy to reimburse for hospital-based outpatient diabetes education.”

In sum, Utah presents as an active program in a state with a small population spread over a fairly large land mass. The population includes Native Americans who are being addressed, in part, through a demonstration project. There is evidence of use of data for decision-making and of an active Advisory Board, as well as a comparatively large staff, despite some gaps in the staffing pattern (epidemiology).

## **4.0 Findings: Surveillance and Use of Data**

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## 4.0 Findings: Surveillance and Use of Data

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In this chapter, we present information regarding access to surveillance data, and use of these data, by **DCPs**. This discussion forms a bridge between core capacity and programmatic output, since public health programs depend heavily on accurate data for decision-making and program planning. The chapter focuses on what CDC has called “defining the burden of diabetes.” The previous chapter focused on the “coordination” efforts of **DCPs**, and the next one will look at efforts in “developing” and “implementing” programs.

### 4.1 Use of the Behavioral Risk Factor Surveillance System

In recent years, CDC has strongly encouraged state programs to take maximal advantage of the Behavioral Risk Factor Surveillance System (BRFSS). However, a limitation of the BRFSS is that it is a telephone survey concerned with many health risks and therefore uses very few indicators for each condition of interest. Modules are added on a rotating basis in order to keep the instrument from being unwieldy. The diabetes module, for example, would be given to only a portion of all those being interviewed with the BRFSS - those respondents who have been told by a physician that they have diabetes. Under such a circumstance, more detailed data are obtainable, but the sample size is very small relative to the total population of the state. We addressed these issues in some detail in order to assess the following feature:

- ***The DCP utilizes the diabetes module of the Behavioral Risk Factor Surveillance Survey (BRFSS), and other key BRFSS questions, to track diabetes morbidity and evidence of care.***

The diabetes module of the BRFSS contains 12 questions that address 10 issues. The issues are (1) age at diagnosis, (2) whether or not the respondent uses insulin, (3) frequency of insulin use (if used), (4) home glucose monitoring, (5) knowledge of glycosolated hemoglobin (**HbA1c**), (6) visits to provider for diabetes care, (7) frequency of **HbA1c** monitoring, (8) foot examinations, (9) dilated eye examinations, and (10) visual acuity. The diabetes module may be included each year that the BRFSS is administered in a state or on a rotating basis. Some advisors to our project thought that the frequency of use of the module is an indicator of the ability of the DCP to leverage a strong position within its health department.

Our findings indicate an increase since 1994 in the number of states that include the diabetes module in the BRFSS, as shown in Table 4-1. Twenty-eight of the states included the diabetes module for 1994, 33 for 1995, and 36 for 1996. There is a 19 percent increase between 1994 and 1996. However, when asked about the next expected year for the implementation of the diabetes module, 34 states (80%) said 1997, a slight decrease from 1996.

**Table 4-1: Inclusion of Diabetes Module in BRFSS**

<b>Year</b>	<b>Number of States</b>
1994	28 (67%)
1995	<b>33 (79%)</b>
1996	36 (86%)

Another way to look at the inclusion of the diabetes module in the **BRFSS** is to consider how often states have done this for the last three years-1994, 1995, 1996. The matrix in Table 4-2 displays the pattern of the inclusion of the diabetes module in the BRFSS over these three years. Twenty-four of the states included the diabetes module for all three years, while only two of the states did not include the diabetes module for any of three years. We have missing data for one state. Only two states included the diabetes module for 1994 and 1995 but not for 1996. None of the states included the module just for 1994 but not for 1995 and 1996. Meanwhile, six states included the module for 1995 and 1996 after not doing so for 1994, while three other states did not include the module for 1994 and 1995 but did so for 1996. These findings suggest that there is a trend among the DCP states to include the diabetes module in the BRFSS more often over time.

**Table 4-2: Pattern of Inclusion of Diabetes Module**

<b>1994</b>	<b>1995</b>	<b>1996</b>	<b>Number of States</b>
Yes	Yes	Yes	24
No	Yes	Yes	6
No	No	Yes	3
Yes	Yes	No	2
Yes	No	Yes	2
No	Yes	No	2
No	No	No	2
<b>Total # per year that use BRFSS</b>			
<b>28</b>	<b>33</b>	<b>36</b>	<b>41*</b>

\* We have missing data for one state.

One way of supplementing the information obtainable from the diabetes module, especially if the module is not administered each year, is to use other indicators from the main body of the instrument. We called indicators especially germane to people with diabetes “key indicators.” They are (1) smoking, (2) cardiovascular disease (CVD), (3) nutrition, and (4) exercise. We also offered respondents the opportunity to tell us about other items that they analyze.

Thirty-eight **DCPs** (91 percent) indicated they use data *from the* main body of the BRFSS other than the diabetes module. The key indicators and the frequencies of their use by the **DCPs** are provided in Table 4-3. We found that between 78 percent and 91 percent of the **DCPs** report using any one of the four key indicators, with the exercise or physical activity indicator being the most frequently used and nutrition being the least frequently used. Indicators that some **DCPs** used in addition to our “key indicators” include (1) general health, (2) obesity, (3) health care accessibility, (4) demographics, (5) alcohol use, and (6) health care coverage.

**Table 4-3: Key Indicators Used From Main Body of BRFSS**

Key Indicators	Frequency (%) of Use Across States
Exercise	38 (90%)
Cardiovascular Disease	36 (85%)
Smoking	34 (80%)
Nutrition	33 (78%)

We also asked respondents who analyzes the BRFSS data and how often. A little over a third of the **DCPs** (n= 15) reported they analyze the data themselves, while two states reported they analyze the data in collaboration with another department or agency. Twenty-two **DCPs** reported that the analysis is done by another agency. Agencies or other organizations that reportedly conduct the analysis of the BRFSS data include the BRFSS Program, statistics department, universities, epidemiology and disease surveillance department, or a health assessment program or branch. Twenty-five **DCPs** reported that the data are analyzed on an annual basis, while seven states reported bi-annual analysis. Table 4-4 presents further information on how often BRFSS data are analyzed.

**Table 4-4: Analysis of BRFSS Data**

How often are BRFSS Data Analyzed	DCP Analyzes Data Itself (Frequency/%)*	DCP Does Not Analyze Data on Own (Frequency/%)**
Annual analysis	10 (67%)	15 (63%)
Bi-annual analysis	4 (27%)	3 (13%)
Analyze every 5 years	0	2 ( 8%)
Analyze on an “as needed” basis	0	4 (17%)
“Propose annual”	1 ( 7%)	

\* Percentages are based on the 15 **DCPs** that perform their own analysis.

\*\* Percentages are based on the 24 **DCPs** that do not perform the analysis on their own.

We also found that all of the **DCPs** with their own epidemiologist analyze BRFSS data annually (n=7) or bi-annually (n= 1). Five of the six **DCPs** that analyze these data on an “as needed” basis, or

every five years, have no epidemiologist at all. The evidence points to the advantage of having a capability for analyzing the BRFSS within the DCP. Without this capability, data are analyzed less frequently.

#### 4.1.2 Use of BRFSS Data

We asked respondents to provide us with up to three examples of how they have used data obtained from the BRFSS. Thirty-nine states provide us with at least one example each. Based upon our review of the responses, we grouped the examples provided by the states into ten substantive categories of types of usage, as follows:

- Obtain specific epidemiological and other types of data on diabetes in the state
- Establish baseline data for program planning, development, and evaluation
- Obtain specific data on other diseases (e.g., CVD)
- Provide data to local agencies
- Use data in education and public awareness materials
- Obtain data on care of people with diabetes
- Use data for CDC cooperative agreement application
- Use data for legislation and public policy
- Use data for funding and budget purposes

The two most frequently cited types of usage of BRFSS data are the obtaining of specific epidemiological and other data on diabetes for a state (**n=28**) and the establishment of baseline data for program planning, development, and evaluation (**n=27**). We realize that the actual usages of BRFSS data included in these two categories may overlap, since obtaining epidemiological and other data on diabetes may well be directly related to the establishment of baseline data for program planning. Also, these first two categories are rather broad, and it is likely that they incorporate some of the other uses cited by respondents. For example, epidemiological data may be used for some of the other purposes listed, such as legislation and public policy. Or, data for a very specific purpose, such as learning about the care of people with diabetes, can be used for program planning. Although evidence in other sections of the survey lead us to believe that this is the case, the extent of the overlap is not clear from the responses.

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### 4.1.3 Barriers to Using Data from the BRFSS

We asked respondents to describe any barriers they encountered in using BRFSS data. As with the examples of usage discussed above, we reviewed the responses and grouped them into substantive categories of types of barriers. These barriers were elicited alongside our question about the use of BRFSS data. They may not represent all the barriers encountered. Nineteen respondents cited the small size or lack of inclusivity of the samples as a barrier. Using data supplied by 11 states, it is apparent that the sample sizes for the diabetes module of the BRFSS are very small. California, a state with a population of nearly 31 million people, with over one million adults with diabetes, uses a BRFSS diabetes sample size of 200 adults. Less populous states reported sample sizes for the diabetes module as low as 50 adults.

Using the BRFSS to its best advantage presents a real challenge for **DCPs**. In order for data obtained with such small samples to be meaningful, one argument is that the module be used and analyzed frequently to measure trends over time. In order for planning to occur, **DCPs** would want to stratify data according to a number of demographic, clinical, and health system variables. However, if they did so, there simply would not be meaningful numbers in each cell, and the confidence intervals would be so wide that there would be little practical value.

**DCPs** have employed a few strategies for overcoming the barrier of small sample size. For example, four states combine data from several years (e.g., five years) in order to get the sample size they want. Another state has used the BRFSS in combination with other national data. Some states are hoping to use regional data, such as data from all states containing Appalachian mountain communities.

The second most common barrier to use of the BRFSS, cited by 12 respondents, is cost and time limitations. Lack of expertise was cited by two **DCPs**. Four **DCPs** were probably referring to attempts to use national data to supplement BRFSS data when they cited the lack of comparability between the two sources. **Also**, one person was concerned about the timeliness of release of CDC data, possibly pointing to use of national data to supplement the state-level BRFSS data.

#### 4.1.4 Enhancing the BRFSS

Given the barriers that are encountered in using the BRFSS, we wanted to know whether **DCPs** carry out specific data collection activities to supplement the BRFSS, especially with regard to reaching populations of people with diabetes that are likely to be undercounted (e.g., indigent people without telephones). The analytic feature which this addresses is:

- *The DCP undertakes a method to enhance the reach of the BRFSS, if appropriate to the state.*

Sixteen state **DCPs** (38%) have conducted data collection to supplement the BRFSS. Thirteen of these states have either done an expanded BRFSS type of survey or a telephone survey. The most frequently cited purposes for the supplementary data collection include a desire to learn more about diabetes among minority populations (n= 10), to identify risks and behaviors in Medicare recipients (n=5), or to simply expand the BRFSS (n=4). Some **DCPs** have used specific indicators - for example, one used laboratory data to discover more about the use of **HbA1c** testing, another looked at hospital discharge data, and another at a dietary practices survey. It is likely that some of these individual examples were not done just as supplements to the BRFSS but as specific data collection activities to learn more about particular problems. By and large, it appears that supplementation of the BRFSS is done to obtain data about target groups that may be under-represented in the already small sample size for the main instrument.

## 4.2 Other Data Sources

During the feasibility study, staff at **DCPs** told us that they were concerned about limiting data collection activities to the BRFSS because the data are simply not robust enough to be useful in many instances. Anecdotal evidence, as well as presentations at national conferences, led us to believe that **DCPs** are increasingly using a variety of data sources, but with serious limitations in accessibility and other limitations in analyzing the data and disseminating findings. Therefore, we asked respondents a series of closed-ended questions to learn more about their experience with varied data sources. These questions addressed the following feature:

- *The DCP is able to use additional **data** sources.*

Forty of the **DCPs** (95 %) reported the use of data sources other than the BRFSS. The four most commonly used data sources include death certificates, hospital discharge records, birth certificates, and the End Stage Renal Disease (ESRD) Registry. Of the data sources we asked about specifically, the ones that are least *commonly* used are diabetes registries, blindness registries, the Health Plan Employer Data Information Set (HEDIS), and pharmaceutical databases. This information is summarized in Table 4-5.

**Table 4-5: Data Sources Used by DCPs**

<b>Type</b>	<b>Frequency (%) Used Across DCPs</b>	<b>Not Used Frequency</b>
Death Certificates	37 (88%)	5
Hospital Discharge	31 (74%)	11
Birth Certificates	26 (62%)	16
End Stage Renal Disease Registry (ESRD)	22 (52%)	19
Blindness Registry	6 (14%)	35
<b>Pharmaceutical</b> Database	5 (12%)	37
Health Plan Employer Data Information Set (HEDIS)	3 ( 7%)	37
Diabetes Registry	2 ( 5%)	40

We were interested in the reasons why **DCPs** do not use the data sources that we enumerated for them. We hoped that such information would allow technical assistance to be addressed to overcoming some of these barriers. In Table 4-6 we present information on the most common reasons why states do *not* use a particular data source. The least commonly used data source is a diabetes registry (with only one DCP reporting access), primarily because it simply does not exist in most states. Registries for blindness do not exist in most states either. Pharmaceutical databases do not exist in 13 states, and in 18 other states, DCP staff either lack access to or do not know how to use the database. For HEDIS, barriers are almost exclusively related to not knowing how to gain access to the data or a lack of adequate staff support for doing so.

**Table 4-6: Reasons Why Data Sources Are Not Used**

Barriers to Using/Accessing Sources of Data* Frequency that Barrier Was Cited							
Type	Source non-existent in state	Legal or privacy issues bar access	DCP lacks funds to access the source	Use of data inconsistent with program objectives	DCP lacks staff to access the source	Don't know how to access the source	Other
Diabetes Registry	39	1	2	0	1	0	0
Blindness Registry	27	1	1	1	2	3	1
Pharmaceutical Database	13	1	4	1	8	10	0
End Stage Renal Disease Registry	7	2	2	0	4	0	0
Health Plan Employer Data Information Set	1	1	3	3	12	13	2

\* Each DCP could cite more than one barrier - unless the barrier was that the source did not exist. If this occurred, we counted lack of existence of the source as the sole response.

Barriers cited for gaining access to the commonly used data sources were somewhat idiosyncratic. We are concerned that we received a total of eight responses saying that either hospital discharge data, death certificates, or birth certificates do not exist in a state. We assume that this means that the source exists but that the particular DCP has a problem gaining access to the data. A common reason, cited seven times, for not using birth certificates was that the use of such data is inconsistent with program objectives. This probably means that the DCP has chosen not to target issues around **gestational** diabetes (GDM) or the pregnant woman with diabetes. A few **DCPs** volunteered information about barriers that were not listed in the survey. These kinds of barriers deal with lack of experience with the source (it is “new in the state”), difficulties in downloading, and poor quality of data.

We also invited the **DCPs** to report other data sources used besides those enumerated in the survey instrument. The reader is cautioned that associated frequencies only reflect what respondents volunteered

and may not reflect all sources of data that the **DCPs** have been using for the past three years or more. For example, nine **DCPs** reported using data provided by Medicaid, but actual usage may be somewhat higher (see Chapter 5.0). Three states mentioned that they use managed care or insurer data; five, **that they** use Medicare data; and one state, that it uses peer review audit data. **DCPs** draw on data available from local health departments, **the** Indian Health Service (IHS), and the state. Four **DCPs** mentioned using the state-specific diabetes plan. National surveys and census data were also mentioned.

### 4.3 Dissemination of Data

In this section, we present information concerning the dissemination of data. We are attempting to use our information concerning types of data disseminated and the persons to whom the data are disseminated as a proxy for use of data collected by the DCP. For example, information may be disseminated to legislators to advocate for improved legislation, an issue that will be discussed further in Chapter 5.0. The feature being addressed is :

- **The DCP *disseminates* data to a variety of *audiences*.**

#### 4.3.1 Dissemination of Written and Oral Information

Thirty-four of **the DCPs** reported they have disseminated information in a written form since July 1, 1994 in order to effect programmatic change. We asked respondents who had disseminated this type of information to provide examples. We reviewed the responses and categorized them based on two criteria: the type or form of written information and **the** audience or recipients of **the** information. The forms of written information are listed in Table 4-7. We found that “reports” are **the** most commonly disseminated form of written information, **with** this type occurring 46 times among all of the examples. The category “reports” includes general research, epidemiological, needs assessment, hospital discharge data, birth defects records analysis, or other statistical reports. “Informational materials, presentations, or campaigns” are the second most common form of written information, occurring **26** times among the examples. **This** category includes pamphlets, state fact sheets, poster presentations, newsletters, resource directories, materials from other organizations or agencies (ADA or CDC), and public information campaigns.

**Table 4-7: Written Dissemination of Findings**

<b>Forms of Written Dissemination</b>	<b>Number of Examples*</b>
Reports	46
Informational materials, presentations, or campaigns	26
Journal articles, publication	8
Diabetes control or strategic plans	5
Form unknown	9

\* **DCPs** were invited to provide up to three examples each.

The other dimension of the dissemination of written information is the “who” - that is, the intended recipients or target audiences. The **DCPs** did not always provide information about their intended audiences in their examples. However, we found that the most frequently cited audience is health care providers (n= 17), who were targeted for informational materials, presentations or campaigns, reports, or journal articles. The second most frequently cited audience are state or local government agencies (other than health departments) or state legislators (n=8). This audience mainly received reports, as well as other informational materials. Other audiences or recipients include: specific communities; participants in diabetes conferences; Medicaid or managed care organizations; consumers, patients, or persons with diabetes; state or local health departments; the general public; and advocacy or voluntary organizations.

Thirty-one **DCPs** reported that they have disseminated information through oral communication since July 1, 1994 in order to effect programmatic change. We asked respondents who had disseminated information in this way to provide examples. As with the written forms of information, we reviewed the responses and categorized them based on two criteria: the audience or recipients of the information and the type or form of oral communication. The forms of oral communication are listed in Table 4-8. As the table demonstrates, the majority of the forms of communication in the examples provided by the **DCPs** are oral presentations (n=53), either at conferences or in another context (such as presentations to organizations or other government agencies).

**Table 4-S: Oral Dissemination of Findings**

<b>Form of Oral Communication</b>	<b>Number of Examples*</b>
Presentation (not at conference)	30
Presentation (at conference)	23
Workshop	4
Unknown**	12
<b>Total:</b>	<b>69</b>

\* DCPs were invited to provide up to three examples each.

\*\* No information about this form of communication was provided to us.

In the second dimension of oral information dissemination, namely the audience, we found that diabetes, public health, or chronic disease conferences are most often the forum (**n=24**) for presentations or lectures. The following audiences were also cited (between four and seven times each): health care providers; advocacy/voluntary organizations; state or local government agencies (not health departments) or state legislators; other state or local health departments; managed care organizations; targeted communities; and other state **DCPs**.

Our results leave us with some concern that state-level diabetes data are most frequently circulated among those who are already somewhat familiar with diabetes issues, as evidenced by the audiences for oral presentations. At the same time, though, we saw that health care providers are a frequent target of information dissemination. With regard to health systems change, we do not yet see much evidence that diabetes-related data are disseminated to decision-makers in the health system. In the next chapter, we will discuss specific activities meant to affect the health system. These activities point to a greater impact than that made through dissemination of data.

## **4.4 Discussion - Relationship of Infrastructure and Surveillance**

In analyzing our data we believed that the most salient relationship between infrastructure elements and access to and use of data would be the presence of an epidemiologist on staff. The results of **chi-square** tests of the relationship between having an epidemiologist (DCP only as opposed to DCP-shared or no epidemiologist) and use of the BRFSS failed to show such a relationship at the 0.05 level of

significance. Similar results were obtained when we considered supplementation of the BRFSS as the dependent variable.

A chi-square test was also done to see if the presence of an epidemiologist means that the DCP is more likely to use the other data sources enumerated in the survey and discussed in Section 4.2 above. We created a two by three contingency table, categorizing use of data into O-1 source, 2-4 sources, and 5 or more sources. Our analysis failed to show a significant association between the presence of an epidemiologist and use of data sources at the 0.05 level.

These findings, of course, may be due to our own small sample size, or **DCPs** without an epidemiologist or other surveillance staff may be successfully finding ways of filling in this gap in their staffing patterns. However, we did see that when a DCP analyzes the BRFSS data itself, it is somewhat more likely to do so on an annual basis than a department external to the DCP would. Furthermore, 25 percent of **DCPs** without the capability of analyzing their own BRFSS data may wait as long as five years for analyzed data or rely on obtaining data on an “as needed” basis.

If we consider the future of **DCPs**, it will be increasingly important that *all* of *them* be able to present and disseminate a variety of data to legislative, managed care, and other audiences. **DCPs** also need to engage in strategic planning, using objectives that can be measured for programmatic outcomes and using those plans to mark their progress. It seems unlikely that **DCPs** will be able to accomplish these goals without the support of an epidemiologist, or similarly trained professional, available on a basis that can support surveillance, data collection, data analysis, and data dissemination,

We have chosen a state with a veteran epidemiologist to highlight in Profile 4-1. As in all the other profiles, it may not be possible to generalize from this to other programs. At the same time, the profile does offer a picture of a DCP with an epidemiologist on staff that shows evidence of using data for decision-making, advocacy, and program planning.

## **Profile 4.1: Surveillance and the Use of Data**

This profile focuses on abilities to access and use data and makes some tentative comments regarding the possible relationship between data capabilities and programmatic efforts. The aggregated survey data have not shown a statistically significant relationship between having an epidemiologist on staff and data-related activities. Still, for this profile we have chosen a state to demonstrate what can be accomplished when a DCP does have its own epidemiologist.

Washington, a state with about 5.4 million residents, had about 162,000 adults with diagnosed diabetes, or 3.5 percent of the adult population, according to the state's own statistics for 1995. It is likely that nearly as many adults have undiagnosed diabetes. CDC data show that the cost of this disease to the state in both direct and indirect costs was about \$1.96 billion in 1992.

The Washington DCP was first funded in 1979. At the time of our survey, its staff of seven people consisted of a Program Director, Program Coordinator, Epidemiologist, Public Health Advisor, Certified Diabetes Educator, Health Educator, and one person for clerical support. However, only the Epidemiologist and Public Health Advisor were with the DCP on a full-time basis. As in most states with a Diabetes Program Coordinator, the Program Director is involved with many programs. The Program Coordinator, active in other high-profile, diabetes-related activities, is employed in this position at a little more than half-time.

The Washington DCP received 95 percent of its funding from the CDC Cooperative Agreement and five percent from a State Prevention Block Grant in FY 1995. In FY 1996 the Washington DCP received 100 percent of its funding from the CDC Cooperative Agreement.

The Washington DCP Advisory Council was established in August 1995. Prior to that time, the DCP had an *ad hoc* group of physician specialists providing support on issues related to complications of diabetes. (Reducing the burden of diabetes due to complications was the focus of the previous cooperative agreement.) Members of the current Advisory Council include representatives from the regional peer review organization, Blue Cross, Medicaid, HCFA, community clinics, managed care, and voluntary diabetes organizations, among others. While activities of the council have focused on setting priorities for DCP activities, the group has also established an "Outcomes Measurement Task Force" to develop a statewide consensus diabetes measurement set. (Further information on this task force is provided below.)

The Washington DCP uses many different data sources for surveillance including, but not limited to, the BRFSS. It uses hospital discharge data, death certificates, birth certificates, ESRD Registry, and HEDIS, as well as data obtained from Medicaid and Medicare.

The diabetes module was included in the BRFSS for Washington in 1994, 1995, and 1996. The sample sizes for the modules of those years were 108, 135, and 125, respectively. The diabetes module will be included in the BRFSS for 1997, with an anticipated sample size of 135. The Washington DCP has conducted data collection to supplement the BRFSS. It conducted a telephone survey targeting Medicare recipients (n= 1 100), the purpose of which was to obtain a broader sample than possible with the diabetes module and to identify risks and behaviors in this “high risk” population in order to develop interventions targeting this group. The Washington DCP worked with the state Peer Review Organization (PRO) that has oversight responsibilities for Medicare. The PRO developed a sampling frame from Medicare data sets and the DCP obtained its sample from this frame.

The DCP also utilizes data from the main body of the BRFSS. For example, it has used such key indicators as: smoking, cardiovascular disease, nutrition, and exercise, as well as obesity, health status, and health coverage. Washington DCP analyzes the BRFSS data itself on an annual basis.

Washington DCP provided examples of how surveillance data has been used for program planning. In one example, it developed an assessment of diabetes at the county level which has been used for county-level planning. In another example, a lack of outpatient data was the impetus for the creation of the Diabetes Outcomes Measurement Task Force, an initiative involving 12 health plans and Medicaid and Medicare. The task force developed 10 indicators that will serve as a measurement set of clinical services and patient outcomes. One of the lessons learned in this case is that it is important to identify unique partners to assist in solving problems. As it turned out, all of the members of the task force have a stake in this initiative in the sense that they want a single set of measurements that apply to all health care providers and clinical settings. The next step is to collect the baseline data, which is dependent upon obtaining additional funds for that effort.

The Washington DCP has also been active in the area of state health care reform, extending coverage of insurance benefits for people with diabetes, professional education, and the development of community-based coalitions. Our survey instrument did not capture the relationship between this individual program’s rather extensive data capabilities and its activities in these areas. However, the use of data for local planning and the outcome task force point to the existence of such a relationship.

**5.0 Findings: Programmatic Activities**  
**Health Systems Change, Health Communications,**  
**and Community-Level Activities**

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## 5.0 Findings: Programmatic Activities - Health Systems Change, Health Communications, and Community-Level Activities

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In this chapter, we discuss our findings concerning the output of programs-what programs can do, given their core capacity. While the survey is descriptive in nature and does not lead to statistical conclusions about outcomes, we can make statements about the level of activity of **DCPs** and make some inferences about the effects of these activities. For example, legislative activity has been common, and this has had the effect of improving benefits for many kinds of patients. The outcomes (whether people use the benefits available and the impact on their health) are not yet known. Finding ways of assessing these more distant events will be a topic of the next chapter of this report.

### 5.1 Health Systems Change

Twenty years ago, when the Diabetes Control Program was initiated, **DCPs** were engaged in a very different health system than today. Most Americans were treated in a fee-for-service setting, and it was assumed that the public health system took up the slack for people who were unable to meet the fees for private health care. As the science for prevention of diabetes-related complications evolved, **DCPs** became demonstration sites for bringing the available technology to the poor and underserved. Then, in the early **1990s**, two things occurred simultaneously. They were (1) scientific evidence that tight control of diabetes could prevent complications, and (2) the promotion of health care reform on a national level. With the demise of efforts toward national health care reform by 1994, initiatives to change health care systems were left to the states. At the same time, the insurance and managed care industries have become increasingly powerful and are seen as ways of holding down health care costs.

In order for **DCPs** to be effective, they now needed to translate the latest scientific evidence in such a way that it was useful to players within the health system, such as **MCOs**, especially those who work with Medicaid patients. A few **DCPs** had experience with these players. For example, one state in our 1994 Case Study<sup>1</sup> had focused its program almost exclusively on the Medicaid population by 1993. We found that another state was beginning the process of planning for changes in the health system when

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<sup>1</sup> Hersey JC, Hare ML, Roussel AE, Butler MO. *Lessons from Implementing State-Based Diabetes Control Programs: An Evaluation*. Report to CDC, DDT, and OPPE; from Battelle-CPHRE, March 1994.

we visited them in the summer of 1993 and in fact, that DCP later became an active player in state health care reform.

When Battelle (with its advisors) designed this study in 1995, it became critical for us to see how all the states were faring in this rapidly changing environment. The bulk of the survey addressed health systems change. It reflected a desire to learn about efforts that may not have gone well, or about issues with which states may not have been as familiar or comfortable as, for example, community-based outpatient education projects (which, of course, continue to be important in an evolving health system). In other words, we wanted to get at issues that might not be reported unless asked about directly, which may not show up in quarterly progress reports. The purpose of collecting this information is to identify strengths and weaknesses across the program, so that further assistance can be offered to **DCPs** from CDC or from states experienced in this area to those which are less experienced.

Of course, it is necessary to take into account the environments in which **DCPs** operate. Some states have many active managed care plans with strong reputations for delivering good health care. Other states have few plans at all, and many are mixed in terms of the reputations and the reach of the plans in their states. We have appendicized an exploratory study<sup>1</sup> that made use of telephone interviews with staff at eight **DCPs** and on-site interviews at three states to learn more about the impact of a state's environment on the DCP. In this chapter, we will first present findings from the survey component dealing with the health systems environment, and then present examples of activities to influence that environment.

### **5.1.1 Knowledge and Activities Concerning Regulators of Insurance and Coverage**

The first feature of interest is:

- *The DCP is knowledgeable about the present health system in the state.*

State health systems can be fairly variable. We were especially interested in learning more about this variation as indicated by gaps in coverage by Medicaid. At the same time we wanted to find out more about whether **DCPs** are able to work with agencies responsible for regulation of Medicaid, insurance, and managed care. First, we asked respondents a series of questions about which particular services are

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<sup>1</sup> **Birch & Davis Associates, Inc.** *Collaborations between Selected State Diabetes Control Programs and Managed Care Plans to Centers for Disease Control and Prevention, April 1997.* [See Appendix C]

covered by Medicaid; then we asked for examples of limitations in coverage. In Table 5-1, we present frequencies for coverage of a service across all states, whether in full or in part. We also give some examples of limitations on coverage that respondents offered. It is important to remember that the situation is quite fluid and only reflects what was occurring as of mid-1997.

The next feature addresses the question of whether **DCPs** are able to influence or work with regulatory agencies or key players in the health system. The analysis feature is:

- ***The DCP, alone or in partnership, has expanded its interactions with Medicaid, MCOs, or other key players in the health system.***

We asked a series of questions about DCP interactions with regulatory agencies for Medicaid, insurance, and managed care. Tables 5-2a, b, and c show whether **DCPs** interact with these agencies alone or with an intermediary and the kinds of activities in which they engage. In sum, 25 **DCPs** (59 percent) show evidence of interaction with regulators for Medicaid, 21 (50 percent) with regulators of the insurance industry, and 21 (50 percent), with regulators of the managed care industry. We see that **DCPs** tend to interact with these agencies along with a partner or possibly indirectly (through an intermediary), although we also have many examples of interactions solely with the DCP.

**Table5-1: Medicaid Coverage for Selected Services Across States**

<b>Type of Service</b>	<b>Frequency (%) Service is Partly or Fully Covered*</b>	<b>Examples of Limitations to Coverage</b>
Medications- insulin	40 (97%)	Restricted to patients requiring insulin or when medically prescribed** For members of Medicaid Managed Care plan One respondent noted there is a capitated rate of 85%
Medications-oral hypoglycemic agents	39 (95%)	Must be in Medicaid Managed Care plan At a capitated rate A few specified medical necessity or physician prescription
Monitoring Equipment	37 (90%)	Several respondents noted that the patient must be on insulin Must be member of Medicaid Managed Care plan Diagnosed before age 30, blind or handicapped, or Type 1
Therapeutic Shoes	21(50%)	Must be under 21 Must be in Medicaid Managed Care plan
Hospital-Based Outpatient Education	20 (48%)	Only at certain sites under a waiver program Must be in a Medicaid Managed Care program (all enrollees or a subpopulation), OR If enrolled in HMO, this is not required Mostly (85%), but not completely capitated In relation to clinic visit or provision of medical services
Outpatient Education not Restricted to Hospital	18 (43%)	Similar restrictions to those noted for hospital-based outpatient education Type 1 patients under age 21 for nutritional counseling only One state covers only in physician fee-for-service setting
Other -Supplies***	7 (17%)	Limited time period Prior authorization and medical necessity
Other -Nutrition Counseling	(2%)	In state's Medicaid Managed Care for people with diabetes
Other - Specialist	1 (2%)	(No comments given)

\* One state did not supply information, therefore the total number of DCPs reporting was 41. Percentages are based on 41 DCP's reporting.

\*\* We suspect this is common practice.

\*\*\* These categories ("Other") were volunteered by respondents. It is possible that some of these categories were incorporated into the responses of other respondents; e.g., supplies with monitoring equipment or nutrition counseling with patient education.

**Table 5-2a: DCP Activities with Regulators for Medicaid**

<b>Types of Interactions with Agency Responsible for Regulating Medicaid Coverage</b>	<b># of DCPs</b>	<b>Types of Interactions</b>	<b># of DCPs</b>
DCP alone*	9	Joint Membership in Advisory Groups, Committees, and similar bodies	2
		Guidelines and Technical Assistance for Drafting Regulations and Legislation	1
		Data Collection/Access, Surveillance, and Research	1
		Discussion/Review About Issues Concerning Joint Clients	1
Through an intermediary	2	Discussions/Review about Issues Concerning Joint Clients	1
		Information Sharing/Requests for Information	1
Roth DCP and through an intermediary**	1	Joint Membership in Advisory Groups, Committees, and similar bodies	3
		Joint Advocacy for Coverage	2
		Discussions/Review about Issues Concerning Joint Clients	2
		Guidelines and Technical Assistance for Drafting Regulations and Legislation	1
		Data Collection/Access, Surveillance, and Research	1
		Information Sharing/Request for Information	1
		Don't Know	1
		"Other"	2
Not applicable	17		

\* Data are missing for four DCPs

\*\* Data are missing for one DCP

**Table 5-2b: DCP Activities with Regulators for the Insurance Industry**

<b>Types of Interactions with Agency Regulating Insurance</b>	<b># of DCPs</b>	<b>Types of Interactions</b>	<b># of DCPs</b>
DCP Alone*	14	Information Sharing/Request for Information	3
		Joint Advocacy	2
		Technical Assistance for Legal Issues	2
		Joint Membership in Advisory Groups, Committees, and similar bodies	2
		Data Collection, Surveillance, and Research	1
		“Other”	3
Through an intermediary	0		
Both DCP and through an intermediary	7	Technical Assistance for Legal Issues	2
		Joint Advocacy	1
		Joint Impact Study	1
		Data Collection, Surveillance, and Research	1
		Drafting Legislation Regulations	1
Not applicable	20		

\* Data are missing for one DCP.

**Table 5-2c: DCP Activities with Regulators of MCOs**

Types of Interactions with Agency(ies) Responsible for Regulating Managed Care Organizations	# of DCPs	Types of Interactions	# of DCPs
DCP alone	10	Information Sharing/Request for Information	5
		Joint Advocacy	2
		Joint Impact Study	1
		Data Collection and Research	1
		Technical Assistance for Legal Issues	1
Through an intermediary	0		
Both DCP and through an intermediary*	11	Joint Advocacy	2
		Joint Impact Study	1
		Drafting Legislation Regulations	1
		Technical Assistance for Legal Issues	1
		Joint Membership in Advisory Groups, Committees, and similar bodies.	1
		Information Sharing/Request for Information	1
		"Other"	1
Not Applicable	18		

\* Data are missing for three DCPs.

We further explored the question of whether **DCPs** could obtain and use Medicaid administrative data. Twenty-four **DCPs** (57 percent) have conducted some kind of surveillance, programmatic, or advocacy activity with Medicaid since July 1, 1994, even though only 18 **DCPs** said that they can obtain data from Medicaid. Below, we discuss the types of activities conducted (ranking them in the order cited by the respondent) and any outcome or evaluative data that some of the respondents were able to share. Each respondent was invited to cite up to three activities. An individual respondent may have cited one or more examples in each of the categories listed.

- **Data collection and surveillance** was the most common type of activity, with eleven examples.

*Results-* A positive outcome was a cost-saving program that was developed by Medicaid, presumably with these data.

Two respondents were concerned about an inability to access data.

- **Assessment and expansion of coverage.** This category had seven examples.

*Results-* Change or improvement in Medicaid policy

Renewal of HCFA waivers

The development of criteria for coverage of supplies

One state said that activities were “tabled.”

- **Joint membership in DCP advisory groups, committees, or coalition.** Six DCPs gave this type of example.

*Results-* The interaction “ensured a diabetes perspective in Medicaid program planning.”

“Medicaid was opposed to legislation ... [and] was not receptive to suggestions or recommendations of the DCP.”

- **Patient or provider education activities** were conducted with Medicaid in five states.

*Result-* “Increased numbers of clinics and hospitals provide reimbursement for diabetes management. ”

- Program **planning** was undertaken in five instances.

*Results-* One program resulted in a cost savings of \$4,500 per participant.

- **Information sharing,** while implied in most or all these examples, was specifically cited three times.

*Results -* Lack of response from Medicaid

- **Managed care** activities were cited twice, with one state noting that it will be initiating Medicaid Managed Care soon.

*Results -* None noted

- **Quality assurance** was cited once but without a description of the activity or results.

Unlike Medicaid, Medicare is guided by Federal rather than by state regulations. Even so, states can affect Medicare policy. However, efforts in this area were rare for **DCPs**. Only three **DCPs** said “yes” to a question about activities to affect Medicare policy, and three others commented on the relationship of the DCP to Medicare. Activities and comments tended to overlap in their nature. Activities cited include:

- DCP provided data to support those who successfully promoted policy change.
- Peer review organization (PRO) members on the Diabetes Council are committed to a quality improvement (QI) project related to diabetes.
- DCP assisted the Medicare intermediary (insurance provider) to develop policy to reimburse for hospital-based outpatient education programs.

Other comments were:

- Collaboration is underway with PRO that may eventually affect Medicare patients.
- While members of the advisory committee have worked on Medicare Legislation, the DCP has not been involved.
- DCP has had no opportunity to affect policy, since state insurance law does not cover Medicare supplementals. (Writer went on to mention that they do communicate Medicare policy to others in the “diabetes community.”)

It is likely that Medicare coverage will improve due to recent legislation that expands benefits to include “monitoring equipment and instructions on how to manage self-care.”

### **5.1.2 Quality Assurance, Quality Control, Quality Improvement**

One area that has been receiving increasing attention is validating and maintaining quality in the health care system. As public health leaders in their states, DCP staff can provide guidance in setting standards of quality care. In an evolving health system, it is especially important that **DCPs** be proactive, letting key players in their states know that they are available and willing to work to improve both access to

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<sup>1</sup> Love, A. *Washington Post* August 8, 1997.

service and quality of service. We knew that some DCPs had worked in the area of quality assurance, quality control, or quality improvement (QA/QC/QI), as noted in our 1994 report of a state that had been working with a managed care organization to gather data on physician practice with the aim of improving adherence to patient care guidelines.

We wanted to know specifically whether the DCPs are working with provider organizations in their states to obtain administrative, surveillance, or QA/QC/QI data from MCOs. Our results show that slightly more than one-quarter (n= 11) of the programs are obtaining such data. Examples of the ways in which such data are used include:

- Informational or in advisory capacity
- Assessment of care for QI project
- Outcome measurement
- Work with agencies within state health department or insurance industry
- Strategic planning
- Determination of provider practices for evaluation
- Obtain HbA1c values for evaluation [through] claims data showing patient practice
- Baseline data for evaluation
- Assess outpatient procedures and costs and identify incident cases of diabetes

Other kinds of QA/QC/QI activities were also mentioned, as follows:

- Work with home health or outpatient agency (three examples)

**Uses** Outcome measurement

- Work with PRO (two examples)

**Uses** Baseline for QI project  
Assess outpatient procedures and costs and identify incident cases of diabetes

- Monitor guideline implementation (two examples)

**Uses** Include QI baseline from plans in assessment report  
Include information about provider activities in strategic planning

- Combined patient survey and chart review (one example)

**Use** Look at HbA1c throughout region

### 5.1.3 Advocacy for Health Systems Change

This section examines activities that are devoted to improving health care for people with diabetes through steps to improve care and access to care, education of providers, and legislative or policy initiatives. We found that many programs are active in this area, and it appears that **DCPs** that lack some critical infrastructure elements (e.g., robust staffing ) are able to make up for weaknesses in order to carry out particular initiatives.

We have come to this conclusion by examining particular features we believed would be associated with an active and effective DCP. Especially important to these findings are the partnerships that **DCPs** have built, because as state employees they may not engage in political activities directly.

#### Access to Services

The feature we are examining is:

- ***The DCP and its partners have taken steps to improve access and delivery of services for patients.***

Since we discovered that most of the activities that address this feature are legislative in nature, we found that it is closely linked to another feature:

- ***The DCP works with its partners to influence legislation to assure that the needs of people with diabetes are served, especially if state health care reform is under consideration.***

We asked DCP respondents to self-report on (1) activities their programs initiated or influenced to affect coverage or reimbursement, and (2) activities initiated or influenced by the DCP to effect policy change in the area of patient access to resources. The examples showed that the most meaningful way to affect access is through improving coverage or reimbursement, an area in which more than three-fourths of the **DCPs** were active. Tables 5-3 and 5-4<sup>1</sup> summarize the kinds of activities in which **DCPs** have been engaged and the partners with whom they have been involved in the area of improving access to care. Each DCP was free to cite one or more partners.

We were interested in getting the biggest picture possible of what **DCPs** do in the areas of advocacy and policy change. This means that we asked about activities undertaken by the DCP and about

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<sup>1</sup> Examples of improved access through coverage were recoded and collapsed in Table 5-3.

those that the DCP influenced, (e.g., through providing a diabetes association with information for a legislative initiative). We explored accomplishments, barriers to achievement, and lessons learned in the areas of improving coverage, reimbursement, or access to outpatient education, patient care services, or supplies.

**Coverage of Outpatient Education, Supplies or Resources, or Services (82 examples).** Most activities were meant to affect the legislative process, particularly through expansion of coverage or increasing reimbursement for particular services. In some cases, the activities did not deal directly with a particular piece of legislation but with recommendations, such as changes to be made in provider contracts. Some activities focused on educational functions. For example, a “seminar on managing costs” geared to insurance executives, medical directors, and claims personnel, was done as a prelude to more work on the coverage of education. Barriers almost exclusively dealt with the political process. Comments include such statements as, “locked in committee,” “killed in committee,” or “powerful insurance lobby.” We were told of a situation where an attempt by pharmacists who were not Certified Diabetes Educators (CDEs) to obtain reimbursement for diabetes education was jeopardizing an amendment to expand coverage for outpatient education. Some states simply experienced an “initial loss” on matters of legislation. Others experienced partial victory, for example, increased coverage of people voluntarily enrolled in Medicaid Managed Care. One piece of advice was to “work with health plans for voluntary change first.”

**Table 5-3: DCP Activities to Affect Coverage and Reimbursement Across All States**

<b>Activities Initiated or Influenced by the DCP to Effect Policy Change in the Area of Coverage or Reimbursement</b>		<b>Partner Types Involved in the Process*</b>						
<b>Activity Type</b>	<b># Activities</b>	<b>State Agency</b>	<b>DCP Advisory Body</b>	<b>Hospital/ Medical School</b>	<b>Academic Organization</b>	<b>Voluntary Organization</b>	<b>None</b>	<b>“Other”</b>
Coverage of outpatient education	32	11	21	8	6	26	0	4
Coverage for supplies	31	13	20	7	5	23	0	2
Coverage for medical services	19	7	13	4	2	16	0	2

**Table 5-4: DCP Activities to Affect Access to Education, Supplies or Services (but not involving increased coverage or reimbursement)**

<b>Activities Initiated or Influenced by the DCP to Affect Policy Change in the Area of Access of Resources for Patients</b>		<b>Partner Types Involved in the Process*</b>						
<b>Activity Type</b>	<b># Activities</b>	<b>State Agency</b>	<b>DCP Advisory Body</b>	<b>Hospital/ Medical School</b>	<b>Academic Organization</b>	<b>Voluntary Organization</b>	<b>None</b>	<b>“Other”</b>
Improved access to outpatient education	17	9	8	5	4	6	1	2
Improved access to supplies or resources	11	6	6	2	2	7	1	0
Improved access to medical services	6	3	5	3	1	4	0	0

\* Note that partner type categories are not mutually exclusive - most states reported multiple partner types for each category.

### **Improved Access to Outpatient Education, Supplies or Resources, or Services (34 examples).**

Accomplishments for improving access, other than those involving coverage or reimbursement, generally had a community focus. For example, one state organized an educator network to improve knowledge and materials, “especially in rural areas.” Another spoke of the use of CDC grant money to set up model diabetes outpatient education programs in underserved areas, and yet another, of **Latino** outreach through peer educators. One state set up partnerships with community colleges, while another expanded outpatient education by organizing classes to be taught by medical students, dietetic interns, and clinic nurses. Legislative activity requiring case management for Medicaid patients was included in this category, as was the promulgation of diabetes resource guides. One interesting piece of legislative activity was writing “legislation to allow day care providers to assist children with blood glucose monitoring.” Another state mentioned regulations for people with diabetes in an HMO giving them the “**right** to see a specialist with experience in treating diabetes.” Barriers dealt mainly with lack of time and lack of penetration into rural areas. A solution is for DCP staff to monitor activities and provide support.

### **Quality of Services**

So far, we have been talking mainly of activities that should have the programmatic effect of improving access to services. Now, we will focus on those activities that should lead to improved quality of care (including preventive care) for people with diabetes or at risk of developing diabetes..

The feature of concern is:

- ***The DCP works with its partners to disseminate standards and guidelines for care and to improve professional education.***

In Table 5-5 we present data describing the kinds of activities in which **DCPs** have been involved to disseminate, update, or draft standards or guidelines for care. Then, in Table 5-6, we present information on DCP activities in the area of providing professional education. After presenting these summary tables of responses to closed-ended questions, we will discuss accomplishments, barriers, and lessons learned or advice shared by the **DCPs** in response to open-ended questions.

**Table 5-5 DCP Activities in the Area of Standards and Guidelines**

<b>Initiatives to Disseminate, Update, or Draft Standard or Guidelines</b>		<b>Partner Types Involved in the Process*</b>						
<b>Type of Standards or Guidelines</b>	<b># Activities</b>	<b>State Agency</b>	<b>DCP Advisory Body</b>	<b>Hospital/ Medical School</b>	<b>Academic Organization</b>	<b>Voluntary Organization</b>	<b>None</b>	<b>“Other”</b>
For physicians	33	10	21	15	11	14	0	1
For other medical care providers	23	9	13	6	8	6	0	0
For diabetes educators	14	4	6	3	4	6	0	0
For managed care organizations	19	6	7	9	5	5	0	1
<b>Standards/guidelines for others:</b>								
Model Benefits Package	5	2	4	2	2	1	0	1
Clinic/Health Center Guidelines	1	0	1	0	0	0	0	0
AADE Guidelines	1	0	0	0	0	0	0	0

\* Note that partner type categories are not mutually exclusive - many states reported multiple partner types for each activity.

**Table 5-6 - DCP Activities in the Area of Professional Education**

Activities DCP Has Initiated or Influenced		Partner Types Involved in the Process*					
Type of Professional Education Activities	#	State Agency	DCP Advisory Body	Hospital/ Medical School	Academic Organization	Voluntary Organization	None
For physicians	34	11	13	15	13	17	0
For other health care providers	34	11	8	10	7	16	1

\* Note that partner type categories are not mutually exclusive - many states reported multiple partner types for each activity.

### **Developing, Disseminating, Implementing, and Updating Standards and Guidelines (96 examples).**

Generally, **DCPs** broke this task down into manageable pieces, many targeting groups such as Managed Care Organizations (see Profile 5-1). A few states are getting away from the use of medical standards and guidelines and using other guidance, such as **continous** quality improvement (CQI) indicators. One state mentioned that it is using American Diabetes Association (ADA) standards for flow sheets and suggested indicators. Others are also using flow sheets, indicators, or algorithms for care. In the main, these efforts appear to be ways of helping providers simplify the task of keeping up with the components of good care for people with diabetes.

Some states reported on activities in process, not only on those that were completed. Others reported instances where another entity, such as the advisory board, had “agreed to draft guidelines.” In a few cases, the DCP or its advisors were in the process of doing a literature review as a prelude for developing indicators or standards. Some guidelines are targeted to minority groups or to people with gestational diabetes. When it came to writing guidelines for **MCOs**, we were told of the need for provider education. One state discussed its office-based education initiatives for different levels of providers.

Most of the barriers cited revolved around issues of time. As one respondent in a state that is re-writing standards for outpatient education said, it is a “long process.” It was also difficult to achieve consensus, especially in a large state with many health plans. One way of achieving buy-in from providers was to conduct focus groups - we were told of a task force that completed focus groups for physicians which helped improve receptivity and recognition of need.

**Professional Education (68 examples).** Much of the professional education occurred through seminars or conferences. We did not ask whether continuing medical education credits (**CMEs**) or continuing education units (**CEUs**) were provided, but a number of respondents indicated that they are. Some used existing venues like grand rounds, and some new venues, such as satellite teleconference or video **self-**study programs, were noted. Optometrists, podiatrists, physicians caring for Medicaid patients, osteopathy students, providers in long-term care settings, and podiatrists were among target groups. A few states targeted local health departments for non-physician education, and one cited an inter-tribal program. Barriers revolved around creating interest, especially among physicians in states that don’t require **CMEs**. Finding a central location or reaching rural audiences was also difficult for a few **DCPs**. Thus, one **solution** would be to use new health communications technology, the subject of the next section of this chapter.

DCPs are strong in developing partnerships and appear to be knowledgeable about their health systems environments. They break tasks down into manageable pieces, such as developing guidelines for a targeted group of professionals, but we do not know the impact of such tasks.

## 5.2 Health Communications

When the survey instrument was designed, health communications was not a large part of the mission of the DCPs. We were aware of some that had worked with media or disseminated brochures, but our questions were aimed mainly at finding out whether the DCP had the infrastructure to eventually carry out activities in this area. Recently, at the March 1997 Diabetes Translation Conference in San Diego CA, conferees learned about a national teleconference devoted to diabetes awareness, to occur in October 1997. For this event, state DCPs were to develop **downlink** sites and perhaps some programming tailored to individual states. In our survey, we did see evidence that DCPs are participating in activities that use various media to reach other professionals, the general public, and people who already have diabetes.

Our questions to states were very broad in scope, addressing the following feature:

- ***The DCP undertakes activities in the area of health communications.***

These activities could be targeted to the entire state, to a group within the state (a category of providers, a minority group) or to local communities. We discovered that, in fact, health communications activities are quite popular among DCPs.<sup>1</sup>

Since July 1, 1994, 38 state DCPs (91 percent) reported they have created or participated in diabetes-related media or other health communications initiatives, either alone or with another agency or organization. In all there are 91 examples of health communications initiatives reported by the DCPs. Of these 91 examples, 14 (15 percent) were done by the DCPs on their own, while 75 (82 percent) were done with another group. We asked the states who participated or collaborated with another group for health communication initiatives to report on who their partners were. The states reported partners for 70 of the 75 examples of collaborative initiatives. We reviewed all of the responses and categorized them into types of partners. The types of partners for health communications initiatives and the number of each type are provided in Table 5-7. The most frequently reported partnering arrangements on health communications

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<sup>1</sup> The DCPs used their own definitions of “health communications activity.”

initiatives are with: affiliates of the American Diabetes Association; other kinds of public, private, and non-profit organizations and associations; and State Health Department Agencies.

**Table 5-7: Partnering Arrangements in Health Communications Initiatives**

Partner Categories	Frequency across Initiatives with Partners*
Affiliate of American Diabetes Association	17
Multiple Organizations for same initiative (including public, private, and non-profit)	17
Other Non-Profit Organization or Association	11
State Health Department Agency	11
Private Sector, (e.g., retail outlet)	4
Affiliate of American Association of Diabetes Educators	3
Local Media Organization	3
Hospital/Medical Center	2
Academic Institution	1
Other Government Agency	1

\* Note that partner type categories are not mutually exclusive • many states reported multiple partner types for some activities.

We asked respondents for examples of activities. This discussion highlights those that are targeted to various local communities or to identified groups of people within states. One western state mentioned a public awareness campaign in the African-American community, while another was targeting Hispanics with “*dichos*” or traditional folk sayings. A northeastern state uses radio and newspaper public service announcements (**PSAs**) to advertise outreach to its Hispanic residents. In the Midwest, a DCP introduced an urban African-American program and has used both newsprint and television.

Another Midwestern state cited more general kinds of programs such as “awareness activities” and glucose screening education in “various communities and primary care centers.” In the southwest, a DCP implemented community awareness campaigns in two communities. Another southwestern state mentioned a fairly ambitious program called “Prevention and Health Awareness are your Greatest Allies.” Patients receive education at 43 sites with the purpose of increasing the use of Medicare-covered preventive services for diabetes. This state also holds town hall meetings in local communities to increase awareness and diabetes knowledge.

**DCPs** use the media. A mid-Atlantic state has participated in a local cable access television call-in health show in which a diabetes nurse appears once a month to address diabetes issues. A rural midwestern state has provided professional education diabetes update programs to rural communities, as well as “train-the-trainer” sessions for providers.

Health communications activities are designed to have an effect on the recipient of the program. While we did not ask for information about programmatic effects or outcomes, these are activities to which evaluations for health outcomes could easily be attached. Since we saw that very few **DCPs** have the services of a media or health communications specialist, but many participate in some kind of health communications activity, this appears to be an area ripe for technical assistance in targeting messages and evaluating their impact.

### 5.3 Community Projects

As we saw, a number of the health communications activities overlap with other kinds of activities discussed in this report, such as patient and provider education, and now, local community-based activities. For the purposes of this study we chose not to emphasize the work that **DCPs** do on the local or community level. These are often detailed in progress reports (a review of several sets of progress reports was undertaken earlier in this study), and we were concerned about respondent burden. We wanted to be sure to detail infrastructure and core capacity and then to focus on health systems change, the most rapidly changing piece of the diabetes program puzzle. Still, no single component of an effective diabetes control program can be divorced from the others. For example, as those **DCPs** that engaged in direct care activities in the past have worked with local communities to take over this function, they may have, through this process, had an impact on the health system.

Our focus in this remaining section on the findings of our survey is to summarize information about *Diabetes Today*<sup>1</sup> and other community-based projects. The feature this addresses is:

- ***The DCP builds the capacity of communities to use data, prioritize needs, and plan interventions for the health goals of the community.***

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<sup>1</sup> ***Diabetes Today* is a course consisting of several modules designed to help members of communities assess their community and plan, develop, and evaluate diabetes interventions appropriate to community members.**

We asked states to report local or community-based programs that have been funded in full or in part by the DCP at any time since July 1, 1994.’ We broke our categories down into (1) *Diabetes Today* programs, (2) diabetes education (other than *Diabetes Today*), and (3) local community-based demonstration projects (not solely education). We asked for the number of programs or projects the DCPs had conducted of these three types and the number of communities in which these programs were conducted. We made this distinction because a program—perhaps a **Latino** outreach program—may be considered a single program, but it could be reaching several communities. However, we believe that some respondents were confused by this distinction, so it is possible that the number of programs is **over-**reported, and perhaps the number of communities is somewhat under-reported. We also asked what the target audiences were for these programs or projects.

About half of the states have undertaken any one of the three types of community-based activities. If we look at the total number of programs or projects across all of the states, we see that there have been 338 diabetes education, 119 *Diabetes Today*, and 111 demonstration projects. The average number of programs or projects per state varies depending on the type\*.

As in the section of this chapter dealing with health systems change, we **sought out information on** special accomplishments or barriers in community-level programming. Our final analysis feature is:

■ ***The DCP identifies barriers at the community level and seeks to address them.***

Some respondents merely gave information about the program without addressing barriers or solutions to problems. Many programs are targeted to particular minority groups. A northeastern state has been targeting both Puerto Rican and African-American women. Elsewhere in New England programming specific to people of Hispanic backgrounds is also available in several communities. Five states mentioned educational or demonstration programs specific to Native Americans. In the mid-Atlantic, difficulties were encountered in hiring a project director for *Diabetes Today* from the local

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<sup>1</sup> Localities may develop diabetes-related activities independent of the DCP, and at times the DCP may not even be aware of the existence of such activities. Or, there can be particular programs targeted to very specific communities that are carried out through a funding stream completely separate from the DCP. Because of these possibilities, we needed to restrict our questions to those activities that use DCP funds. As shown in Chapter 2, such funds may include other sources than the CDC cooperative agreement.

<sup>2</sup> For example, the average number of demonstration projects is 4.4 per state, *Diabetes Today* is 5.6, and diabetes education is 15.4. However, there is less variation if we look only at the median number of programs for each of these types. While the average for diabetes education programs is relatively high compared to the other two types, it has a slightly lower median in comparison. This is due to the wide range for the number of programs per state in this category.

community, however, a community diabetes education program in the same state was found to be particularly successful with middle-aged African-American men.

As in every other component of diabetes programming, working in partnership is important to carrying out community-level programming. Local health departments were the settings for a number of the demonstration projects. Although only one respondent specifically mentioned collaboration with local public health departments, we were told of other successes with county agencies and local public health departments. Churches are venues for outreach and “empowerment” activities. A western state mentioned a university partnership in diabetes education. A Midwestern state partnered with a cardiovascular disease coalition to better serve people with diabetes in a “free clinic.”

Activities varied from cooking classes in New England to case management in the South. Technical assistance, lifestyle intervention and education, local resource libraries and local needs assessments were mentioned one or more times by different states. One Midwestern state is working with four communities to develop a “system to assure comprehensive care for indigent people.” While we did not specifically ask about evaluation of the programs, five states volunteered this information for their demonstration programs. These comments are:

- Increased referrals and support for diabetes education
- Expanded capacity of county agencies to offer outpatient diabetes education and nutritional counseling.
- Improvements in adherence to standards of medical care to patients with diabetes.
- Improved care in 120 agencies and five local health departments.
- Statistically significant improvements in clinical care provided to minorities with diabetes.

A problem cited by one of the state respondents was that the ***Diabetes Today*** program is “too dependent on the DCP [and therefore] a sustainability problem.”

## **5.4 Discussion - Programmatic Effects**

This chapter looked at the output of programs in three areas. We took a detailed look at health systems change and then a brief look at health communications and at community-based activities. DCPs are working to affect the health systems in their states, mainly in the area of partnering to extend coverage

and access to education, care and resources. **DCPs** also continue to work in areas that have been their strong points in the past - disseminating standards and guidelines and supporting professional and public education. These activities are designed to affect the quality of care, including preventive care. We can therefore say that programs have been undertaken that affect the health systems environment, consumers, and educators, but we do not know their degree of penetration or the health outcomes associated with these programs. For a number of these efforts, though, it should not be difficult to develop some measure of impact in the future.

Health communications and community-based activities affect both access to care and quality of care. It appears that some evaluation has already occurred for small-scale demonstration projects showing improvements in health outcomes. With additional technical assistance, it should not be difficult for **DCPs** to evaluate these outcomes further. However, considering the small staff of most **DCPs**, the need for evaluation assistance from an outside source (e.g., a local university) for most states is likely. A strategy for dealing with this need will be part of the subject of the next chapter.

In this chapter, we have chosen two states to profile (Profiles 5-1 and 5-2), hoping to shed some more light on both the process of influencing health systems change and some of the effects of this process.

## Profile 5.1: Health Systems Change and Policy Advocacy

We have chosen two states to highlight in this portion of the report. One is a very large southern state, Texas, and the other is a very small New England state, Rhode Island. They were chosen because **they** are core programs with a large number of health systems activities in place. The exercise of choosing states for these profiles points out the fact that there are no typical state programs. (For other highlights of specific state activities in health systems change, see Appendix C.)

**Texas**, with a population of about 17.6 million people, had a diabetes prevalence rate of 6.5 percent or 865,347 cases according to the state's BRFSS data. 1994 CDC data estimated that perhaps another 400,000 or more adults have diabetes but are not yet diagnosed. CDC estimates of the direct and indirect cost to the state stood at about \$8.5 billion in 1992.

Texas has one of the largest program staffs of all the **DCPs**. Staff include a full-time Program Director, a **full-time** Communication or Media Specialist, a full-time Program Nurse, a full-time Nutritionist, a full-time Health Educator, and two program or field consultants along with five clerical staff (four of whom support the DCP solely). Surveillance and epidemiologic support, combined, are less than half-time, though.

Texas' DCP has had a legislative mandate for its existence since May 1983. It receives 90 percent of its funds through the state. Texas has an independent Diabetes Council that reports to the legislature. The DCP has also been able to leverage small amounts of support from pharmaceutical companies for specific activities.

The Diabetes Advisory Council includes a Managed Care Work Group as one of its standing committees or task forces. This Work Group developed a document, "Minimum Standards for Diabetes Care Under Managed Care in Texas," in 1995. These standards also include a treatment algorithm for Type 2 Diabetes.

The DCP, alone and with an intermediary, has worked with the state Department of Health and the Department of Insurance, and with the state's Diabetes Association on legislation in the areas of Medicaid, insurance regulation, and regulation of **MCOs**. It did not cite any activities concerning Medicare. The Medicaid collaboration involved use of hospital discharge data for a five-county service area.

Legislative areas of interest have included coverage of outpatient education, supplies, and medical services. The DCP reports greater success in the first two areas, to date. There is also legislation pending for case management services for Medicaid patients.

Texas is unique, not only in size, but in the large amount of support it receives for diabetes-related activities directly from the state. However, the profile may be instructive for other programs, in that it points to the successful use of a partnership of highly placed individuals from health plans, academia, an urban coalition, and elsewhere. This partnership developed a consensus statement of what good management entails that is based on current standards and targeted to **MCOs** throughout the state.

## Profile 5.2: Health Systems Change and Policy Advocacy

Rhode Island, with a population of about 1 million people, reported 38,533 adults (or 5.5 percent of the state's adult population) with diabetes in 1994. CDC data also estimated that diabetes cost the state of Rhode Island 527 million dollars in 1992 through the cost of medical care, lost productivity and premature mortality.

Established in 1979, the RI DCP has always had a small staff. Presently, the staff consists of one full-time staff person, its Program Director, who has been with the program since 1980. Epidemiologic support, at three-fourths of full-time equivalency, is shared with Cancer Control and Project ASSIST (a smoking cessation program). Clerical support is at half-time. (Staffing has increased somewhat since the date of our survey with the addition of a full-time administrative assistant.)

The RI DCP is funded completely through the CDC Cooperative Agreement. It has also leveraged funds from pharmaceutical companies to support its Diabetes Outpatient Educator (DOE) program. In-kind support (meeting space and refreshments) comes from hospitals, a Visiting Nurse Association, and a few other individuals or groups.

Rhode Island has an active Advisory Council with several standing subcommittees or task forces. One such subcommittee is targeted to minorities, the uninsured and underinsured, as well as the homeless. Health systems issues cross-cut the work of a number of the other subcommittees too.

One accomplishment of the Diabetes Advisory Council is the passage of legislation that mandates coverage of supplies and services. Lessons learned along the way of accomplishing this goal are the need for strong partnerships and the fact that having a person with diabetes connected with the bill is useful. Letter-writing and telephone calls to legislators, an organized diabetes educator program, and a Diabetes Day for Legislators also raised awareness. Testimony was delivered by physicians, educators, consumers, and the state diabetes association. Within state government, the DCP worked closely with those agencies that regulate insurance and managed care.

In Rhode Island, nurses, **dieticians** and pharmacists certified through the state's DOE program are able to negotiate with third party payers for direct reimbursement. RI DCP provides a third party Reimbursement Directory on an annual basis which includes information on Medicaid and other payers. The DCP stated that it had not directly affected Medicare policy during this funding cycle, but it has been working with its state diabetes association to address federal legislation on diabetes supplies and services. Also, the DCP has negotiated with Medicare since the 1980s regarding reimbursement for diabetes education in the hospital setting.

The RI DCP has worked on disseminating standards and guidelines to three of the state's largest MCOs. It is also working with the agencies that regulate MCOs on evaluating outcomes according to HEDIS measures.

The RI DCP considers health systems issues to be a part of its endeavors to reach members of the state's communities, as in its *Diabetes Hoy* program (Diabetes Today) which is targeted to Hispanic Rhode Islanders. Rhode Island is also one of three states that has received funds from CDC to assess two tools to screen people not presently diagnosed with diabetes.

Unlike Texas, Rhode Island is a small state with a small DCP. Its primary impact in the area of health systems change has been in the passage of legislation mandating coverage of a broad array of services (including physician-referred self-management education) and supplies by both individual and group health insurance plans. Activities with MCOs were initiated before the present funding cycle and continue. A common feature between these two states is an active advisory council.

## **6.0 Conclusions - Developing an Evaluation Strategy**

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## 6.0 Conclusions - Developing an Evaluation Strategy

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In this chapter, we begin by briefly summarizing the findings presented earlier in our report, focusing on strengths and weaknesses of the DCP as seen through our survey. We then turn to the issue of developing a strategy for evaluation of the DCP core programs. We will especially consider the challenges that have been posed in linking programmatic processes with measurable outcomes and then with health impacts. These considerations are discussed in light of new developments both in clinical science and in the health systems environment. We end the chapter with recommendations and concluding comments.

### 6.1 Strengths and Weaknesses of the Diabetes Control Program

The DCP, presently conducted through cooperative agreements with 50 states and four US-affiliated jurisdictions,<sup>1</sup> revolves around core public health functions of leadership and dissemination. The program does not provide direct service to patients, except, in a few cases, through special grants to local health departments or community clinics. However, **DCPs** can choose to affect the quality of care at small settings like primary care clinics through education, technical assistance, or other means. **DCPs** are very much encouraged to work with leaders in health systems, whether they are government leaders or key players in Medicaid, insurance, or managed care. As such, even when focusing on health communications or the local community, **DCPs** are functioning within a health systems change paradigm.

CDC rightfully gives **DCPs** a great deal of leeway in how they conduct their programs. Even so, **DCPs** receive guidance regarding CDC's expectations on what each DCP can accomplish.<sup>2</sup> They can be summarized as:

- **Define the burden of diabetes.** This includes, but is not limited to, an ability to obtain and use surveillance data.
- **Develop new programs.** These programs should address the areas of health systems change, health communications, and community-based activities. In developing new

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<sup>1</sup> Our survey was mailed to 42 states that had received cooperative agreement funds by the end of 1994.

<sup>2</sup> Division of Diabetes Translation. *State-Based Programs to Reduce the Burden of Diabetes: Guidelines for Program Design, Implementation, and Evaluation*. National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, March 1994.

programs, partners are used, and the state may disseminate its own grant funds to local demonstration projects.

- **Implement measures.** These measures are meant to ensure that accepted standards and approaches to reducing the burden of diabetes are adopted.
- **Coordinate activities.** Throughout the process of defining the burden and developing and implementing new programs, **DCPs** must exercise their public health leadership function of bringing together all constituents concerned with diabetes issues, whether through advisory groups, educational and awareness activities, or providing assistance and support to local or other entities carrying out programmatic efforts.

One of the main strengths of the DCP, as framed by CDC, is that the variability within state health system environments is respected, and therefore staff in state diabetes programs are encouraged to be responsive to these environments. Data available for this report cannot accurately reflect the degree of variation and reasons for some states focusing on one programmatic effort, perhaps at the expense of others. This can only be done accurately by focusing on each state DCP. Even so, we felt that it was important to gain an overview of how the DCP is meeting the demands of today's dynamic health system across states.

One of the most important findings of this study is that **DCPs** are most active and comfortable in **coordinating activities**. All but one state has made use of advisory groups during this funding cycle. Our information concerning membership is limited to a subgroup within the sample - the new **members** among the advisory groups for the 25 **DCPs** that were funded from 1989 through 1994. New members were most likely to come from voluntary organizations that are concerned with diabetes (e.g., **state** diabetes associations, state diabetes educator association). There were not a large number of incoming representatives from managed care joining these 25 programs. However, if we look at peer review organizations, Medicaid, insurance, and managed care together, we see 15 citations of these sorts of new members.

**DCPs** conduct a large number of activities with partners, whether members of advisory groups, staff in other state agencies, local or community-based staff, or others who are taking part in a particular initiative. Because DCP staff are forbidden to lobby, one area where partners have been critical has been in advocating for policy change through legislation. Our findings show a great deal of movement toward instituting legislation that extends coverage for outpatient education, patient care, and for resources and supplies. Partners participate in developing and disseminating guidelines, standards, or in some cases algorithms, flow sheets, or CQI indicators. These **accomplishments** are detectable programmatic outputs, even if their health impacts are not easily quantifiable.

The DCPs have been making considerable efforts in *defining the burden of* diabetes, however there are limitations in the tools available to many of them. Even programs with limited access to epidemiologic support obtain data from a number of sources, including but not limited to the BRFSS. A number of states have conducted efforts to supplement the BRFSS or to simply do their own studies of burden (for example, small scale patient surveys or chart reviews). Most states have disseminated findings in some way, largely through presentations at conferences or internal reports. Published articles are rare.

An effective system to monitor the burden of diabetes using surveillance data should enhance the ability of programs to do strategic planning. Slightly more than half the states have a strategic plan for diabetes, whether at the DCP level or state level. It appears that the distinction between a DCP level plan and a state level plan is not clear, and that DCPs that plan at the program level include input from stakeholders outside the program. State-level plans were more likely to use measurable indicators for objectives, but we did not see much evidence of strategic planning objectives being evaluated. This may be due in part to the complex nature of the objectives, requiring several process and outcomes measures to assess their implementation. Some DCPs choose to use recommendations that do not lend themselves to outcomes-based measurements, and two DCPs indicated that they are in the process of developing a strategic plan.

Our questionnaire was heavily focused on infrastructure, core capacity, and the health systems environment in the states. We frequently asked for examples of accomplishments but, for the most part, did not focus on the *development of new programs*. Our impression is that DCPs were very much concerned either with starting up the state program (17 states in the sample) or with meeting the demands of the new cooperative agreement (that is, of being a public health leader rather than a direct service provider). DCPs were active in advocacy for people with diabetes and continued to be strong in education. This translated to a large number of activities in health communications. At the community level, education of minorities or other specific target groups was emphasized. We did not see as much evidence of specific programs with players in the health system as we did of initiatives that were carried out with diabetes advocates and other organizations to influence the health system. Therefore, if we define the word “program” broadly, there was certainly a great deal of activity that extended the reach of DCPs through advocacy and policy initiatives.

We did not capture much evidence of the *implementation of new measures to achieve programmatic objectives*. This was a reasonable finding, considering that the focus of the DCP has changed considerably since 1994 and that so many states were new to the program during this funding cycle. Our sense from the survey, attendance at national meetings, and the several progress reports we have read is that DCPs are spending much of their time looking for new avenues, accessing information, and supporting current programs that are consistent with the goals of effecting health systems change. It

may still be another year or so before clear evidence of programmatic implementation is apparent. It should be noted, though, that where supplemental funding is available, as in the enhanced DCPs, a great deal of effort has been expended in developing and implementing programs. Another example, from a program with considerable state funds, would be the Standards and Guidelines for Managed Care Organizations profiled in Chapter 5, which were intended to reach managed care organizations (MCOs) across Texas.

In addition, we saw that a number of states are involved in community-based efforts and that they are using health communications approaches. Reported successes in this area are ones where DCPs do assessments of need and follow through with programs targeted to particular communities or provider groups. Some states are very creative in this approach. One DCP, for example, conducts educational activities at the stores of a well-known retailer located in sparsely populated areas of the state. In other states, it appears that energy and effort is given to moving into the new paradigm at the state level, with less focus on individual communities.

In Table 6-1, we present a summary of strengths and weaknesses as seen through the results of the survey. Then we discuss information specific to the health systems environment in selected states with significant managed care penetration.

**Table 6-1: Strengths and Weaknesses of Diabetes Control Programs**

<b>Infrastructure</b> ( <i>Staff, resources</i> , partnership building with state agencies)
<p><b>Strengths are.</b></p> <p>DCPs are active in state health departments as evidenced by service on committees and participation in work groups or special initiatives.</p> <p>Three-fourths of DCPs leverage in-kind support for a variety of activities or needs.</p> <p><b>Weaknesses are.</b></p> <p>Discontinuities have existed in program coordination for significant periods of time, and several DCPs are currently without such leadership.</p> <p>Thin staffing patterns are the norm (a structural problem largely beyond DCP control).</p> <p>Lack of funding for the DCP as a whole outside of CDC Cooperative Agreement.</p>

Core Capacity - Advisory Structure
<p><b>Strengths are.</b>  Most DCPs use advisory groups to extend programmatic reach and to conduct policy or advocacy activities.  A few states are “shaking up” old structures - many are bringing in new members.</p> <p>Weaknesses may <b>be</b>:  We saw little evidence that advisory activities are evaluated for their impact, or even for their completion.</p>
Core Capacity - Strategic Planning
<p><b>Strengths are:</b>  Evidence of movement towards developing strategic plans.</p> <p>Weaknesses <b>are</b>:  <b>Only</b> a little more than half the DCPs use strategic planning.  Where strategic plans exist, evaluation of strategic planning objectives was not evident.</p>
Surveillance and Use of Data
<p><b>Strengths are:</b>  Increased use of diabetes module of Behavioral Risk Factor Surveillance System (BRFSS).  About two-thirds of states analyze BRFSS annually.  BRFSS is used to obtain data for program planning.  Efforts are in place to supplement the BRFSS in a number of states.  Most DCPs are able to obtain data from sources other than BRFSS.  More than three-fourths of states <b>disseminate</b> data.</p> <p><b>Weaknesses are:</b>  Structural problems exist that are largely beyond the control of the DCP; e.g., issues over access to data, small BRFSS sample size.  Some variables most relevant for program planning and evaluation are not included in readily available tools.  We saw little evidence that data are linked to evaluation of own program.</p>
Programmatic Efforts - Health Systems Change
<p><b>Strengths are.</b>  Half or more of all states work with Medicaid, insurance companies or MCOs.  DCPs are active in efforts to extend coverage of education, resources, and care.  DCPs are active in guideline and standards dissemination, showing evidence of a trend to target these products <b>to</b> specific audiences or-for specific needs.  Nineteen DCPs cited MCOs as the target for guidelines or standards.  DCPs use partners to accomplish these activities.</p> <p>Weaknesses <b>are</b>.  A significant minority of states still do not appear to be working directly with, or with a representative from, Medicaid, insurance or <b>managed care</b> (if a significant player).  We saw little evidence that health svstems efforts are evaluated.</p>

<b>Programmatic Efforts - Health Communications</b>
<p><b>Strengths are.</b> Most <b>DCPs</b> use health communications to reach out to providers, patients, or general public</p> <p><b>Weaknesses may be:</b> Few <b>DCPs</b> had staff with specific expertise in this area. We did not see evidence of formative, outcome, or impact evaluation.</p>
<b>Programmatic Efforts - Community Activities</b>
<p><b>Strengths are:</b> <b>DCPs</b> reach out to targeted populations such as minorities, Medicare recipients. There was some evidence of outcomes evaluation of specific educational or demonstration programs for target groups.</p> <p><b>Weakness may be:</b> <b>Our data</b> were not comprehensive enough to address weaknesses in community-based activities. We are concerned that the relationship between these activities and health systems change may not be clear for all <b>DCPs</b>.</p>

#### 6.1.1 Efforts in Health Systems Change - Improving Access to and Quality of Care

A particular focus of this study has been DCP efforts in an era of rapid change in the health system. We wanted to **know** how **DCPs** meet this challenge. Success in these terms requires support from CDC, from state government, and from other **DCPs** who may be further along the learning curve. This is because **DCPs** need to be allowed to try something new, even if proof of impact is not apparent for some time. In this section, therefore, we take a broad view of “strengths and weaknesses,” going beyond actual accomplishments to consider creativity and risk-taking as strengths. We especially focus on efforts to improve access to and quality of services through influencing the system for delivering health care, health education, and prevention messages. The survey showed that **DCPs** are moving in the direction of improving access to care, mainly through influencing the legislative process such that coverage of education, patient care, and resources is improved. Efforts in standards and guidelines dissemination, the other area in which a large number of **DCPs** is active, are meant to improve the quality of care.

For states in which there are active managed care organizations, CDC has strongly recommended partnering **with MCOs** as a way to link the statewide public health perspective with the clinical perspective of providers. In 1995, “CDC formed an agency-wide Managed Care Working Group to guide its efforts to foster partnerships between public health agencies at the national, state, and local levels and the rapidly

growing managed care industry to promote prevention and improve the public's health.” One area for which the working group expressed concern was in building capacity for public health agencies to work with MCOs as they enroll underserved populations.

In late 1996, an exploratory study of collaborations between managed care and several DCPs was undertaken (Appendix C).<sup>2</sup> This study highlighted three states - Minnesota, Oregon, and Washington - that are concerned with improving both access and quality of care. These DCPs and their partners put a lot of effort into developing guidelines, or, as in Washington, a measurement set for evaluation of clinical outcomes. Collaboration to improve surveillance was also undertaken, an effort that was sometimes constrained by certain issues like the ownership of information by managed care plans. Although the process has been time-consuming, these efforts appear to be bearing fruit as evidenced by Minnesota's Project IDEAL, which has been pilot testing data collection methods and tools in three health plan clinics.<sup>3</sup>

The process of creating collaborations between managed care and public health cannot be separated from the products of these collaborations. These states are concerned with evaluation of their efforts both from a process point of view (how the collaborations have been working) and to see if there is evidence that the collaborations have reduced the burden of diabetes. As these and other DCPs reach the point of evaluation, it will be crucial for them to disseminate their findings to those DCPs not yet at the stage of evaluating their health system change partnerships. Obviously, we are aware that the DCP is not a homogeneous program, but we believe that states can be excellent resources for each other, since concerns do repeat across programs. This has been evidenced by our survey, and we have seen useful dissemination of program-based planning and evaluation information at national conferences. In the next section, we will discuss ongoing evaluation from a national perspective.

## 6.2 Developing an Evaluation Strategy

The DCP underwent a major shift in focus in 1994, as well as a major expansion. We believe that state-based DCPs continue to be more comfortable with programmatic efforts than with evaluation, but we see several trends that demonstrate increasing comfort with using data for decision-making.

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<sup>1</sup> CDC. "Prevention and Managed Care: Opportunities for Managed Care Organizations, Purchasers of Health Care, and Public Health Agencies" in *Morbidity and Mortality Weekly Review (MMWR)*. US Department of Health and Human Services, November 17, 1995, Vol. 44, No. RR-14.

<sup>2</sup> Birch & Davis Associates, Inc. *Collaborations Between Selected State Diabetes Control Programs and Managed Care Plans*. April 1994.

<sup>3</sup> B&D, *Op.cit.*, page 18.

- **DCPs** are able to obtain surveillance data. Furthermore, they are familiar with the importance of basing decisions on a reliable source of information about the population of interest, and some employ staff who are expert at doing this.
- **DCPs** are advocates for health systems change in their states. They work with partners to affect legislative policy and use available data to accomplish policy-related goals.
- **DCPs** are run by dedicated professionals who take advantage of opportunities to disseminate information about diabetes in their states or about their programs.

In other words, state-based DCP staff want and need outcomes-based data for their own program goals and objectives.

In 1995, Battelle completed a report on evaluation for decision-making for the National Center for Chronic Disease Prevention and Health Promotion (**NCCDPHP**).<sup>1</sup> It was found that grafting indicators onto already functioning programs was not a good strategy. Rather, Battelle recommended that evaluation be an integral part of all programmatic activities from the beginning.

Figure 6.1 presents a model for evaluation that is based on a continuum of activities. This continuum begins with a situation assessment and moves through strategic planning, process evaluation of programmatic outputs, and then to assessing the program outcomes. Our findings show that **DCPs** can move towards **this** kind of integration because they are experienced in working with partners and in thinking about the impact of particular activities on a larger system.

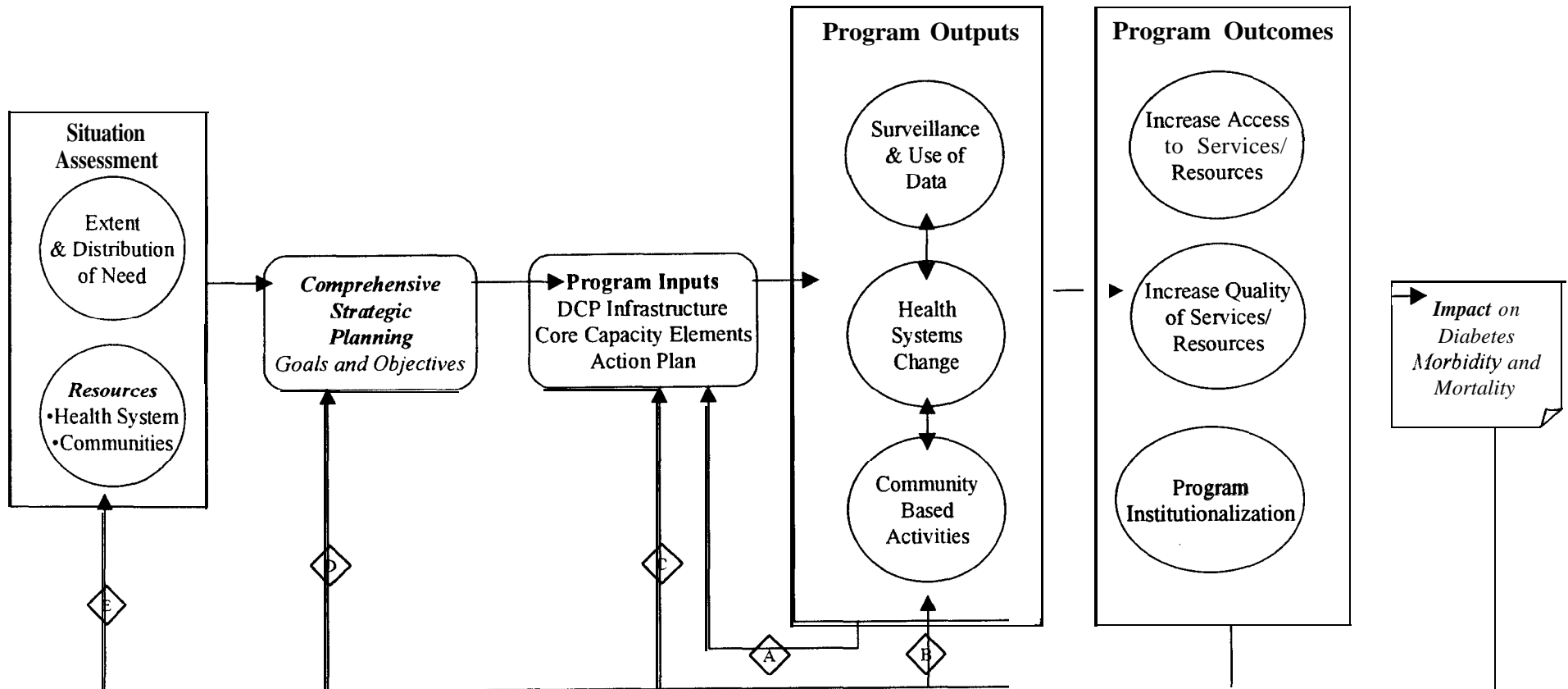
The problem of lack of staff in core programs can be partially solved by creating partnerships with universities, research groups of health plans, or with state agencies, to name a few sources of evaluation assistance. Hopefully, partnerships may also improve access to proprietary data. At the same time, CDC may need to provide technical assistance (TA) in identifying and measuring programmatic outcomes for some **DCPs**, and **DCPs** will need to provide assistance to their state-based evaluation partners in identifying outcomes particularly relevant to populations with high prevalence of diabetes. In this way, **DCPs** further enhance their strength as public health leaders in the state, encouraging all who target activities to people with diabetes, to evaluate those activities and share the results.

Our proposed evaluation strategy rests on monitoring and evaluation capabilities that require ongoing efforts, and the ability to learn about specific populations within a state. Some issues around accomplishing this with tools presently available will be discussed later in this chapter. For now, it is important to note that monitoring and evaluation link all the steps in the continuum, as shown by the letters

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<sup>1</sup> Butler, MO, Hare, ML, Abed, J, and Murray M. *Development of a National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) Evaluation for Decision-Making Strategy to CDC, NCCDPHP* (Contract No. 200-93-0626, Task 01), by Battelle **CPHRE**, April 1995.

**Figure 6.1 Evaluation Strategy for State-Based DCPs**



**Monitoring and Evaluation**

- A) Are program activities (outputs) being implemented as planned?
- B) Are activities (outputs) achieving desired outcomes?
- C) Reassess needs, resources and action plan
- D) Are strategic planning goals and objectives still appropriate?
- E) Is the program leading to reduced burden of diabetes situation changed)?

(A through E) in the diamond-shaped boxes. In addition, improved data capabilities should make it possible to assess whether DCP-related activities, or the influence of the DCP on other systems in the state (e.g., **MCOs**, provider organizations, educational or advocacy groups), has contributed to an impact on diabetes morbidity.<sup>1</sup> We realize this is a distal event. Therefore, we focus most of our discussion through Figure 6.1 Evaluation Strategy for State-Based **DCPs** the level of program outcomes. However, by keeping the issue of health impacts in mind, even at the planning stage, goals and objectives are targeted to the population needs of the state. Finally, using this model, data can be collected so that CDC can make statements about the influence of the DCP across states.

We are aware that evaluation and research tools can be burdensome to staff charged with carrying out programs, especially if staff is not large. Therefore, we see any future evaluation strategy as being one that can easily be incorporated into the functions the **DCPs** presently perform.\* We propose the following three prongs for program-based evaluation:

- Each DCP needs to have a strategic plan based on a realistic situation assessment;
- Quarterly or progress reporting should provide an opportunity to describe infrastructure and core capacity elements and the programmatic outputs that are linked to the objectives of the strategic plan;
- **DCPs** should be encouraged to investigate the outcomes associated with strategic planning through targeted evaluation studies of particular activities meant to meet objectives for increasing access to and quality of service for populations of interest.

### 6.2.1 Strategic Planning and Reporting Mechanisms

**DCPs** are required to develop objectives and ways of evaluating those objectives when they apply for CDC funding. In addition, just over half of states now have strategic plans for diabetes. We believe that all states should engage in strategic planning for diabetes. As seen through the examples cited in Chapter 3.0, state-level strategic plans were more likely to use indicators of changes in health conditions (e.g., a measurable decrease in lower extremity amputation) than DCP-level strategic plans. For DCP-level plans we saw objectives that were more programmatic in nature, such as implementing educational or awareness campaigns.

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<sup>1</sup> **Assessing impact on mortality requires a discussion of the flaws in the ways such data are kept, so we will only imply that improvements in morbidity should eventually have an impact on mortality.**

<sup>2</sup> **Activities to define the burden of diabetes (monitor), develop and implement programs, and coordinate activities.**

It appeared that DCP-level strategic planning was not done in a vacuum. The distinction between a DCP-level plan and a state-level plan deals more with the staff responsible for the strategic plan, than with whether or not there is input beyond the DCP into the strategic planning process. In fact, we believe that it is necessary to develop the kinds of measurable objectives noted slightly more frequently in state-level strategic plans if these plans are to be a critical component of an ongoing long-range evaluation strategy. At the same time, programmatic objectives are also necessary as part of an Action Plan that translates strategic planning objectives into specific programmatic activities for meeting those objectives.

Designing the strategic planning process may take time, especially since objectives need to be developed in partnership with state health department staff and advisory partners. If the DCP does not have its own surveillance staff, baseline data must be obtained through the staff of other departments. This is critical since planning must rest on thorough knowledge of need and resources (situation assessments). Once the process is in place, though, time spent on evaluation is incorporated throughout the activities of the DCP. Reporting is no longer a burden; rather, it helps show where the DCP has gone and where it needs to go in order to have an impact on the health of its target population.’

Another way of keeping the process of strategic planning within limits that are realistic for DCPs, given their small staffs, is to focus the process on two key questions:

- How are the activities for meeting each strategic planning objective improving access ?
- How are the activities for meeting each strategic planning objective improving quality?

We believe that by focusing on improving access and quality, the DCP will have a strong impact on the health system so long as those without access or sufficient quality of services are identified. When speaking of access or quality we refer to objectives that affect the health system on all levels of prevention - primary, secondary, and tertiary. This is in line with the clinical issues discussed in Chapter 1 .O, both in terms of early detection’ and prevention of complications.’

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<sup>1</sup> An example of a strategy for planning and evaluation for Cancer Control can be found in: P. Lillquist, et.al. “Cancer Control Planning and Establishment of Priorities for Intervention by a State Health Department” in Public Health Reports. Nov.-Dec. 1994, 109 (6) 791-803.

<sup>2</sup> **Diabetes Info**, “New Recommendations to Lower the Diabetes Diagnosis Point,” <http://www.diabetes.org/ada/nwclass.htm>

<sup>3</sup> Fertig, Simmons and Martin. Op.cit., page 519 ff.

One way of keeping track of progress toward meeting objectives would be to individualize progress reports' so that each DCP reports on strategic planning objectives and benchmark indicators for meeting those objectives. The reports could contain topic headings, such as surveillance and use of data. health systems change, health communications, and community-level activities. Each state could supply its own strategic planning objectives and document progress towards meeting them through process and outcome measures. Also, the DCPs could cite barriers if progress has been slow or make a statement if the objective is being put aside. In this way, reports on programmatic output, i.e., activities for meeting objectives and limited measures of their effects, would be documented on a regular basis.

### 6.2.2 Assessing Program Outcomes

By linking evaluation to progress reporting, we can accommodate the variability across state DCPs while focusing on the main health system concerns of access and quality. However, we do not believe that progress reports should be the sole method of evaluation. Progress reports are first and foremost a communications tool.

CDC and Battelle have discussed the pros and cons of presenting a checklist to states and asking them to assess themselves. A difficulty we have encountered in the past is the problem of developing assessment questions for a multiplicity of health system environments, and programmatic approaches. We have come to the conclusion that this variety is not a hindrance to evaluation and program planning so long as basic criteria are met. We suggest four broad criteria that can be considered at the outset of strategic planning. They are:

- The system provides technically and culturally competent health education.
- The system provides access to and use of basic preventive services.
- The system assists patients to comply with diabetes control measures including early detection and follow-up to prevent or delay onset of complications.
- The system provides access to and use of cost-effective clinical services for complications and their follow-up to prevent or delay progress from mild to severe complications and death.

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<sup>1</sup> **In January 1997, Battelle met with several Division of Diabetes Translation Project Officers to discuss the matter of progress reporting. We learned that the Division was in the process of streamlining the reports. Concerns expressed were that the reports were often unwieldy in size, reached the Division some time after the events discussed, and were not comparable across states.**

These criteria would hold whether the patient enters the health system through Medicaid, a managed care organization, or a private provider. They also hold whether objectives are targeted to the health system in the state, to a community, or to a local-level provider. Table 6-2 links these criteria with possible processes and logical programmatic outcomes. This could be a model for a state-level outcome study.

### 6.2.3 Assessing Impact on a State and National Level

It is clear that we will always need to recognize our limits in drawing conclusions about the impact of each DCP on diabetes morbidity and mortality in the state as a whole. Even so, in our current public health funding environment, programs must be able to demonstrate that they make a measurable difference. While none of the hypothetical outcomes in Table 6-2 necessarily showed population-based health impacts, if carried out consistently by a large number of providers within the health system, they should lead to early case finding and to reduction of complications.

In the long run, being able to demonstrate an impact on health, requires solid capabilities in surveillance and monitoring. This means being able to acquire and use data through appropriate staff and data collection tools. In the short run, it is necessary to return to the concept of the Situation Assessment, as shown in Figure 6.1. Through this assessment, the need as shown by the distribution of underserved populations is assessed. It is only through such an assessment that the impact of the program on identified populations can eventually be evaluated.

In a similar vein, improvements in identifying target populations, and in ongoing monitoring and evaluation, should yield more meaningful data across states. In this way, statements can be made about the impact of the DCP on various underserved populations throughout the nation. State-based **DCPs** are free to identify the target population, interventions and activities that make the most sense considering the needs and resources in each state. At the same time, **DCPs** are guided to focus on needs that also meet national standards. Accomplishing this dual goal-state-level planning and evaluation, and providing information for assessing national impact--does require expansion of current surveillance, monitoring, or data collection capacities at the state level. This is an issue we shall address before concluding with more narrowly-focused recommendations.

**Table 6-2: Evaluating Outcomes Using Suggested Criteria for Health Systems  
that Meet the Needs of People with Diabetes  
(An Evaluation Matrix for a Hypothetical Program)**

Criterion	Programmatic Process	Programmatic Outcome
The <b>system</b> provides technically and culturally competent health education.	The DCP works to extend coverage of outpatient education so that <b>CDEs</b> associated with providers in underserved neighborhoods are reimbursed by Medicaid Managed Care.	-80 percent of newly diagnosed diabetics enrolled in Medicaid Managed Care attend diabetes education sessions. -Six months after completion, a survey of attendees shows that 50 percent of attendees are exercising four or more times a week.
The system provides access to and use of basic preventive services.	The advisory group for the DCP is working with the state diabetes association for passage of legislation to assure that <b>all</b> adults age 45 and older receive a baseline fasting plasma glucose ( <b>FPG</b> ) and then a repeat FPG on an <b>annual</b> or triennial basis as needed.	-One year after developing this partnership, such legislation is passed for all persons covered by health plans within the state. -A survey conducted one year after passage of the legislation in conjunction with "Major Health Plan" shows that 40 percent of primary care providers ( <b>PCPs</b> ) associated with that plan conduct <b>FPG</b> for all adults age 45 and above. (A new program is then developed to increase to the rate 80 percent of <b>PCPs</b> .)
The system assists patients to comply with diabetes control measures.	The DCP helps to fund and provide technical assistance for a local demonstration project that works with patients at three rural health clinics to monitor their blood glucose.	- <b>18 months after</b> implementing the project, <b>HbA1c</b> levels for patients in the program decrease by 1 percent.
The system provides access to and use of clinical services for complications and their follow-up.	Three years after a member of the research branch of a large health plan joins the <b>DCP's</b> advisory group, she forms a task force to develop a study of referral patterns for annual eye exams, comparing staff model <b>HMOs</b> with group model <b>HMOs</b> .	(It takes <b>two</b> years to field the study) -The study shows that there is no statistically significant difference in the referral patterns between the two models, but that neither model is referring at recommended <b>intervals</b> . (A new program has been in place for one year) -Patients in the program are being referred for eye exams annually, but only 70 percent are following through on the referral. (A behavioral scientist is called in to enhance the program) -For three years in a row, 85 percent of patients in the program receive an annual eye exam.

## 6.2.4 Monitoring and Evaluating Progress

Ideally, a goal of a state Diabetes Control Program (DCP) is to use all means available to see that those who are at risk of acquiring diabetes, or who already have been diagnosed with diabetes, have access to the technologies capable of preventing and/or controlling the disease and its complications. Consequently, one purpose of an evaluation strategy is to measure progress in seeing that the population of the state has unimpeded access to diabetes-related services. It should be noted that there is a possibility that, as time goes by, the proportion of those who have access to needed technologies could decrease, despite the hard work and efforts of a state DCP, for reasons unconnected to the program. But no matter what happens, it is the responsibility of the DCP to monitor whether access is increasing or decreasing. The DCP can then provide evidence as to why these trends are occurring and propose strategies to improve access or address the causes of decreased access.

Consequently, an evaluation strategy should be based on the following:

- An assessment that provides a reasonable estimate of the proportion of the state's population who are at risk of acquiring or already have diabetes, but who do not have access to the technologies capable of preventing and/or controlling the disease or its complications..
- As part of the assessment, instruments that help characterize **underserved** populations.

Who are these populations?

Where do they live?

What factors are impeding their access to the appropriate technologies?

What resources are available<sup>1</sup> that could be mobilized to improve their access to the appropriate technologies?

- Based on the data obtained from the assessment, **DCPs** can develop realistic objectives. These objectives should be clearly defined. Objectives should state how they will be achieved, by whom, and with what resources.
- **DCPs** need to identify which indicators provide the best estimates of progress toward defined objectives. This implies developing indicators and instruments that are particularly sensitive for measuring changes that occur in underserved populations. Statewide averages may be misleading, since underserved populations are under-represented in provider-based surveys. This is partly because these population groups are easily missed in surveys, especially those that use the telephone. Many other barriers, such as language, culture, mobility, unsafe

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<sup>1</sup> These resources could be within the DCP, within the local, state, and federal health departments, within the health sector, within other sectors, or within specific geographic communities.

neighborhoods, geographical isolation, and illiteracy contribute to the under-representation of underserved populations in conventional data gathering for program monitoring and evaluation. Therefore, DCPs need to be able to design and use methods and instruments for assessing population groups within the state.

- Improvements could also be made to existing data-gathering tools using non-targeted approaches such as the BRFSS. For example, the diabetes module could ask when the interviewee was diagnosed with diabetes and whether he or she had complications at that time. This would provide an indirect measure of whether early disease detection (screening of high-risk populations) was being effective. Other questions could ask about self-management of blood glucose and patient education.

Once state-level data are collected, they can form a national database on underserved populations across states. Whether data are collected through targeted, or non-targeted means, some data can be pooled across states for regional planning. With regard to national level evaluation, trends for particular populations can be monitored.

We realize that the evaluation strategy we have proposed appears ambitious. Yet, if each DCP undertakes the development of a solid strategic plan with influential stakeholders in the state, other elements of the strategy should fall into place. For example, it may be possible to influence the state health department to support improved monitoring and surveillance. This is because knowledge about populations at risk of, or with high prevalence of diabetes, is also useful for other chronic disease efforts. In addition, this strategy may require some technical assistance from the federal level for many of the states.

## 6.3 Recommendations

In this section we will limit ourselves to a specific set recommendations that we believe can be accomplished, even within the infrastructure restrictions discovered in the survey. The recommendations pertain to core programs only. They are divided into two categories - program and evaluation. Even so, our first overarching recommendation is:

- Integrate evaluation into programs such that all objectives and all activities to meet those objectives are based on data.

For each recommendation we make, we can name one or many states that already practice it or technical assistance (TA) at national meetings that has addressed the need. Therefore, we make a second overarching recommendation:

- Strengthen and increase venues for **DCPs** to teach each other about their successes - and their failures.

Other recommendations are:

### **Programmatic recommendations**

- TA must emphasize that all activities - communications, local or community-level - have an impact on the health system.
- Take advantage of creative ways of developing infrastructure and core capacity. For example, one state has used grants for university-based researchers to supplement frozen positions in the DCP.
- In order to be proactive about bringing a variety of key players in health systems to the table as partners, look for a variety of venues for participation that fit with the person's time, schedule, and interests, such as a particular time-limited task force.
- In the area of health communications, **DCPs** should be assisted in using techniques to target audiences, develop a profile of audiences, and evaluate the impact of a message or intervention on the target.
- Health communications technology should also be used to enhance the visibility and stature of the diabetes program within the state as a way of gaining attention for the problem of undiagnosed or under-treated diabetes.

### **Evaluation Recommendations**

- An evaluation strategy should be based on a strategic plan for diabetes focused on issues of access and of quality.
- Encourage targeted assessments to discover the needs of, and resources available to, underserved population within each state.
- Address limitations in the BRFSS through (1) aggregating data across states within the same region, (2) crossing some of the data from the demographics section in the BRFSS with data from the diabetes module, and (3) following trends over a number of years.
- Develop partnerships to overcome barriers in obtaining proprietary data and for evaluation assistance.
- Include a consideration of the cost-effectiveness of diabetes programs when assessing health outcomes and health impacts.
- Link outcome studies to a model of an effective health system (technical and cultural competence, access to preventive services, support in control measures, and access to good quality interventions).

- Continue to encourage **DCPs** to focus on underserved populations and create a national database of findings from assessments of these populations, and outcomes of interventions targeted to them.

## 6.4 Conclusions

In this study, we presented the findings of a survey of state-based diabetes control programs that had received funding by late 1994. These 42 states were encouraged to be responsive to the health systems environment in their individual states. They were also expected to carry out core public health leadership and coordination functions, including gathering and using surveillance data, bringing together **diabetes-**related constituencies, and developing and implementing programs. Our survey focused on the infrastructure and core capacity in place at the **DCPs** and on health systems change activities.

We found that most **DCPs** are small programs relying on a few staff, not all of whom are available to the program on a full-time basis. Most programs are reliant on CDC funding, although a few receive fairly large sums from their states. Almost all programs use partnerships to extend the reach of the staff and to advocate for policy and legislative change. In this way, the DCP is clearly having an impact on the health system. At the same time, diabetes has gained attention on the national front, meaning an increase in funds to federal agencies. This has occurred when scientific knowledge has shown that early detection of new cases, and tight control of blood sugar levels in existing cases, can make a real difference in preventing vascular complications of the disease.

During the **1990s**, diabetes control programs have grappled with failed national health reform and with state health reform that may not always assign the highest priority to the needs of poor and underserved people - the clients of public health programs. **DCPs** are making themselves more visible within their states and nationally. They are working with unconventional partners while maintaining some mainstays of the DCP - educational and community demonstration projects. As this report goes to press, the DCP will be participating in a national teleconference.

We believe strongly, as we did when we completed our case study in 1994, that **DCPs** should be encouraged to grow in ways that are appropriate to their own states. Still, we have shown (1) that **DCPs** have undertaken a number of similar efforts and have met common barriers, and (2) that outcomes can be linked to the processes described here. In the future linking these outcomes to processes, it is possible to demonstrate an impact on diabetes and its complications. In this way, **DCPs** can become more visible players in their states by influencing health systems to improve access to care and quality of care for all people with diabetes or at risk of the disease. Ultimately, this will lead to a better public health environment.

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## **Appendix A**

### **Framework of Indicators for a Program Evaluation**

#### **Strategy for Diabetes Control Programs**

### Framework of Indicators for a Program Evaluation Strategy for Diabetes Control Programs

Basic Infrastructure Elements		
Topic	Proposed Indicators	Possible Approaches
Core Staff	<ul style="list-style-type: none"> <li>■ Types of staff (e.g., epidemiologist)</li> <li>■ Dedicated versus shared staff (number of full-time equivalent [FTEs])</li> <li>■ Contractor versus civil service</li> <li>■ Experience of staff</li> </ul>	List FTEs by position and employment status (e.g., state employee, contract staff). Data on experience considered to be of secondary importance.
Leveraging	<ul style="list-style-type: none"> <li>■ Amount of funds leveraged by source</li> <li>■ Amount of in-kind support leveraged by source                             <ul style="list-style-type: none"> <li>— FTEs of paid staff</li> <li>— Volunteer staff (value of time)</li> <li>— Equipment (e.g., glycosometers)</li> <li>— Space</li> </ul> </li> </ul>	Checklist format. (Convert in-kind support to “dollars leveraged.”)
Institutionalization	<ul style="list-style-type: none"> <li>■ Identifiable organizational locus for program</li> <li>■ State mandate for program</li> <li>■ State appropriations for program</li> </ul>	Checklist or short answer format. (Note cross-over of indicators in these first three categories.)

### Framework of Indicators for a Program Evaluation Strategy for Diabetes Control Programs (continued)

Basic Infrastructure Elements		
Topic	Proposed Indicators	Possible Approaches
Advisory Councils	<ul style="list-style-type: none"> <li>■ Type of group (e.g., advisory group to DCP, advisory group to Governor, coalition) <ul style="list-style-type: none"> <li>— Authority under which group was established</li> <li>— Representation on the group</li> <li>— Ability to lobby</li> <li>— Efficacy of advocacy</li> </ul> </li> <li>■ Products of the group</li> </ul>	Create a simple checklist of the products of the group. Complement this with a narrative description of particular accomplishments.
Strategic Plan	<ul style="list-style-type: none"> <li>■ Current strategic plan <b>for</b> the state</li> <li>■ Specific action items with dates <b>for</b> achievement</li> <li>■ Progress to achievement</li> </ul>	Assess accomplishment through <b>percentage</b> of objectives <b>attained</b> or a list of action items accomplished.
Relationship to other health department offices and state agencies	<ul style="list-style-type: none"> <li>■ Examples of work with other offices <i>within</i> health departments</li> <li>■ Examples of work with other state agencies <i>outside</i> health departments</li> </ul>	Checklist with room for narrative.
Health Communications	<ul style="list-style-type: none"> <li>■ Number of staff at the state level, departments in which they are located, amount of time spent on diabetes-related projects</li> <li>■ Examples of statewide health communications initiatives</li> <li>■ Type of health communications expertise at the community level</li> <li>■ Examples of local health communications initiatives</li> </ul>	Checklist supplemented by a short answer format.

**Framework of Indicators for a Program Evaluation Strategy for Diabetes Control Programs (continued)**

<b>Surveillance Elements</b>		
<b>Topic</b>	<b>Proposed Indicators</b>	<b>Possible Approaches</b>
BRFSS and Survey Data	<ul style="list-style-type: none"> <li>■ Frequency of diabetes module</li> <li>■ Sample size for the diabetes module of the Behavioral Risk Factor Surveillance System (BRFSS)</li> <li>■ Population and sample size of special surveys</li> </ul>	Request narrative regarding steps taken to overcome limitations in sample size and frequency of reporting.
Other Surveillance Data Sources	<ul style="list-style-type: none"> <li>■ Hospital discharge data</li> <li>■ Death certificates</li> <li>■ Birth statistics</li> <li>■ End Stage Renal Disease registry</li> <li>■ Blindness registry</li> <li>■ Other (specify)</li> </ul>	Checklist of surveillance data sources used. Supplement with the scope of the data collection (e.g., statewide, substate). Barriers are of interest and should be considered if they do not make the instrument too cumbersome. They may include: source does not exist in the state, source is not accessible by computer, legal/privacy barrier to access, lack of funds, lack of computer staff.
Dissemination and Use of Data	<ul style="list-style-type: none"> <li>■ Checklist of <b>dissemination</b> (e.g., report, journal publication, presentations)</li> <li>■ Describe instances when surveillance data were successfully used for policy development or for advocacy</li> </ul>	Checklist of dissemination (e.g., report, journal publication, presentations). Describe instances when surveillance data were successfully <b>used</b> for policy development or for advocacy.

**Framework of Indicators for a Program Evaluation Strategy for Diabetes Control Programs (continued)**

<b>Health Systems Elements</b>		
<b>Topic Area</b>	<b>Proposed Indicators</b>	<b>Possible Approaches</b>
Coverage, Reimbursement, and Managed Care	<ul style="list-style-type: none"> <li>■ Legislative or regulatory changes effected                             <ul style="list-style-type: none"> <li>— Mandated coverage for diabetes services (e.g., supplies, education) either by insurance or by health care reform</li> <li>— Mandated community rating for insurance</li> <li>— Mandated access to surveillance data</li> <li>— Resources for diabetes</li> </ul> </li> <li>■ Access to data                             <ul style="list-style-type: none"> <li>— Medicaid</li> <li>— Managed care organizations</li> </ul> </li> </ul>	Checklist with request for description.

**Framework of Indicators for a Program Evaluation Strategy for Diabetes Control Programs (continued)**

<b>Health Systems Elements</b>		
<b>Topic Area</b>	<b>Proposed Indicators</b>	<b>Possible Approaches</b>
Policy Advocacy	<ul style="list-style-type: none"> <li>■ Coverage                             <ul style="list-style-type: none"> <li>— Improved coverage for outpatient education</li> <li>— Improved coverage for supplies</li> <li>— Improved coverage for services</li> </ul> </li> <li>■ Improved access to care                             <ul style="list-style-type: none"> <li>— New programs providing diabetes services</li> <li>— Increased number of outpatient education programs</li> <li>— Increased number of screening programs</li> </ul> </li> <li>■ Increased resources                             <ul style="list-style-type: none"> <li>— Increased resources for supplies</li> <li>— Other (specify)</li> </ul> </li> </ul>	<p>Invite narrative to supplement checklist. (Issues are similar to legislation and regulation. May be tied to state health care reform.)</p>

**Framework of Indicators for a Program Evaluation Strategy for Diabetes Control programs (continued)**

<b>Health Systems Elements</b>		
<b>Topic Area</b>	<b>Proposed Indicators</b>	<b>Possible Approaches</b>
Education and Guidelines	<ul style="list-style-type: none"> <li>■ Professional and patient education                             <ul style="list-style-type: none"> <li>— Professional education for physicians</li> <li>— <b>Professional</b> education for other health care providers</li> <li>— Patient education</li> <li>— Development of Standards of Care by medical societies</li> </ul> </li> </ul>	Find out who developed guidelines and how.
Improvements in Quality of Care	<ul style="list-style-type: none"> <li>■ Implementation of Quality Improvement in Health Care                             <ul style="list-style-type: none"> <li>— QA activities</li> <li>— Audits</li> <li>— Representation on committees</li> </ul> </li> </ul>	Request description.
<b>Community Elements</b>		
<b>Topic</b>	<b>Proposed Indicators</b>	<b>Possible Approaches</b>
Community Development	<ul style="list-style-type: none"> <li>■ Number of communities the DCP is working with to support efforts to improve services for diabetes                             <ul style="list-style-type: none"> <li>— Number of communities involved in Diabetes Today Programs</li> <li>— Communities involved in other efforts</li> <li>— Special achievements of these activities.</li> </ul> </li> <li>■ Special populations, communities, or medical service organizations, with which, or for which, the DCP developed special programs</li> </ul>	<p>Open-ended questions asking for number of communities, populations, organizations; types of programs; brief descriptions of special accomplishments or achievements.</p> <p>Descriptions of communities, programs, and special achievements.</p>

## **Appendix B**

### **Survey Instrument**

OFFICE ONLY		
ID#	..... [ ] [ ] - [ ] [ ] [ ] [ ]	
DCP FACILITY: .....		
DATE REC'D: . . . . [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]		
	MM DD YY	

## A SURVEY OF STATE-BASED DIABETES CONTROL PROGRAMS

*Conducted for:*

Centers for Disease Control and Prevention (CDC)

*Conducted by:*

Battelle Memorial Institute

Public reporting burden of information is estimated to average two hours per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to DHHS Reports Clearance Officer; Paperwork Reduction Project (0920-0404); Rm 531-H, H.H. Humphrey Bldgs; 200 Independence Ave., SW, Washington, DC 20201.

# **A SURVEY OF STATE-BASED DIABETES CONTROL PROGRAMS**

*Conducted for:*  
Centers for Disease Control and Prevention (CDC)

*Conducted by:*  
Battelle Memorial institute

**INSTRUCTIONS:** Please ✓ or respond in the appropriate answer boxes. Please do not write in any shaded boxes or spaces marked "OFFICE".

## I. INFRASTRUCTURE AND CORE CAPACITY ELEMENTS

### SECTION A: Diabetes Control Program Staff

Sections A and B ask questions about the resources available to your program. Some items are concerned with changes that have occurred over time.












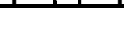







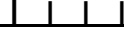

#### INSTRUCTIONS FOR QUESTIONS A1-A5:

- Column A1: Using the Program Positions List found below, indicate the title that **best** describes the position held by each **state-level** staff member now affiliated with the Diabetes Control Program (DCP). If a title doesn't appear on the list, please write it in Column A1. **Place only one position on each line.** If one person has more than one position, title or role, please select the **one** position code that **best** describes the person's job.
- Column A2: Indicate the full-time equivalent (FTE) status of this staff person for DCP-related work, as a **proportion (e.g., 1.0, 0.8, etc.)** of one full-time position.
- Column A3: Indicate the sources of funding for this person by placing the **proportion of total salary** covered by each indicated source.
- Column A4: Indicate if the position is solely dedicated to the DCP or if it is shared with another department. **If shared, indicate with which department.**
- Column A5: Indicate the length of time the position has been **filled** in months. **(If the position is presently open** or if the position has been filled **intermittently**, please provide this information in the chart on page 3.)

#### Program Positions List

01 =	Program Director	07 =	Certified Diabetes Educator (CDE)
02 =	Program Coordinator	08 =	Clinical Nurse Specialist/Program Nurse
03 =	Epidemiologist	09 =	Nutritionist
04 =	Other Surveillance	10 =	Health Educator
05 =	Public Health Advisor (PHA)	11 =	Program/Field Consultant
06 =	Communication or Media Specialist	12 =	Clerical Support

## State-Level DCP Staff Members

A1.		A2.	A3.				A4.		A5.	
State-Level Staff Member <b>Position</b> Affiliated with DCP		FTE Status for DCP Work by Proportion	Proportions of Sources of Funding for This Employee				DCP Only or Shared? Please ✓ one		# Months Position Filled	
<i>Please use the codes in the Program Positions List found on p.2</i>			CDC coop Agreement	Other Federal	State	Contract or Grant	DCP Only	Shared	If shared, specify with what department(s)	# Months
	06	.25	.10			.90	<input type="checkbox"/>	<input type="checkbox"/>	Shared with all programs in Chronic Disease Division	18
1.							<input type="checkbox"/>	<input type="checkbox"/>		 
2.							<input type="checkbox"/>	<input type="checkbox"/>		 
3.							<input type="checkbox"/>	<input type="checkbox"/>		 
4.							<input type="checkbox"/>	<input type="checkbox"/>		 
5.							<input checked="" type="checkbox"/>	<input type="checkbox"/>		 
6.							<input type="checkbox"/>	<input type="checkbox"/>		 
7.							<input type="checkbox"/>	<input type="checkbox"/>		 

A6. Are any state-level DCP staff positions currently open?

☐ Yes - Please continue.

☐ No - Skip to Section B.

**INSTRUCTIONS FOR QUESTIONS A7-A9:**

Column A7: Using the codes provided below, list the positions which are **dedicated solely to the DCP**, but which are **presently open**. If a title doesn't appear on the list, write it in Column A7.

Column A8: Write in the **amount of time** the positions have been open in months.

Column A9: Add any comments you may have. For example, if the position was approved, but a hiring freeze ensued; or if the program prefers a full-time dedicated staff person, but would be willing to share with other programs; enter those comments.

**Program Positions List**

01 =	Program Director	07 =	Certified Diabetes Educator (CDE)
02 =	Program Coordinator	08 =	Clinical Nurse Specialist/Program Nurse
03 =	Epidemiologist	09 =	Nutritionist
04 =	Other Surveillance	10 =	Health Educator
05 =	Public Health Advisor (PHA)	11 =	Program/Field Consultant
06 =	Communication or Media Specialist	12 =	Clerical Support

**State-Level DCP Staff Positions Currently Open**

	<b>A7.</b>	<b>A8.</b>	<b>A9.</b>
	Presently Open DCP Positions	# Months Position Open	Comments
	<i>Please use the codes in the Program Positions List found above</i>		
	03	18	A state hiring freeze has prevented us from <b>filling</b> this position.
1.	<div style="border: 1px solid black; width: 20px; height: 20px; display: inline-block;"></div>	<div style="border: 1px solid black; width: 20px; height: 20px; display: inline-block;"></div>	
2.	<div style="border: 1px solid black; width: 20px; height: 20px; display: inline-block;"></div>	<div style="border: 1px solid black; width: 20px; height: 20px; display: inline-block;"></div>	
3.	<div style="border: 1px solid black; width: 20px; height: 20px; display: inline-block;"></div>	<div style="border: 1px solid black; width: 20px; height: 20px; display: inline-block;"></div>	
4.	<div style="border: 1px solid black; width: 20px; height: 20px; display: inline-block;"></div>	<div style="border: 1px solid black; width: 20px; height: 20px; display: inline-block;"></div>	

## SECTION B: Funding

**INSTRUCTIONS FOR QUESTIONS B1-B3:**

Column B1: Please ☒ Yes or No for each source of funding listed for the **overall** DCP budget.

Column B2 & B3: Insert the **proportion of total funds** for each source for Fiscal Years 1995 and 1996. (We are assuming a fiscal year runs from July 1 to June 30.)

B1.			B2.	B3.
Source of Funding	YES	NO	Proportion 1995	Proportion 1996
a. CDC Cooperative Agreement	3	<input type="checkbox"/>		
b. Other Federal funding	<input type="checkbox"/>	<input type="checkbox"/>		
c. State Prevention Block Grant	3	<input type="checkbox"/>		
d. Other State funding	<input type="checkbox"/>	<input type="checkbox"/>		
e. Other (Specify): <div style="border: 1px solid black; width: 200px; height: 20px; margin-top: 5px;"></div> <div style="border: 1px solid black; width: 200px; height: 20px; margin-top: 5px;"></div>	<input type="checkbox"/>	<input type="checkbox"/>		
f. Other (Specify): <div style="border: 1px solid black; width: 200px; height: 20px; margin-top: 5px;"></div> <div style="border: 1px solid black; width: 200px; height: 20px; margin-top: 5px;"></div>	<input type="checkbox"/>	<input type="checkbox"/>		

CONTINUE ON NEXT PAGE

**SECTION C: Organizational Structure and Partnership Building**

*Section C is concerned with the relationship of the DCP with other agencies within the State Health Department, with state agencies outside the State Health Department, and with the development of partners within the community. Questions concerning formal advisory bodies are in Section D.*

**CI.** To whom does the DCP Coordinator report?

TITLE: \_\_\_\_\_

--	--	--

**c2.** Does your DCP have a legislative mandate?

☐ Yes

☐ No - Skip to C3

A. When was this mandate instituted?

Date: ..... 

--	--

 Month 

--	--	--	--

 Year

**c3.** Have staff members of the DCP served on any committees of the State Health Department (SHD) since July 1, 1994?

☐ Yes

☐ No - Skip to C4

CONTINUE ON NEXT PAGE

### Program Positions List

01 =	Program Director	07 =	Certified Diabetes Educator (CDE)
02 =	Program Coordinator	08 =	Clinical Nurse Specialist/Program Nurse
03 =	Epidemiologist	09 =	Nutritionist
04 =	Other Surveillance	10 =	Health Educator
05 =	Public Health Advisor (PHA)	11 =	Program/Field Consultant
06 =	Communication or Media Specialist	12 =	Clerical Support

**C3A.****C3B.****C3C.**

On <b>which SHD committees</b> did the DCP staff member(s) serve?	What is the <b>position or title</b> of the DCP staff member who served on this committee? <i>Please use the Program Positions List found above. If a position is not on the list, please write it in below.</i>	In what <b>capacity</b> did the DCP staff member serve? Was it as a member, advisor, or officer? <i>Please ✓ only one response per committee.</i>
1. <div style="border: 1px solid black; width: 100px; height: 20px; margin-left: 300px;"></div>	<div style="border: 1px solid black; width: 100px; height: 20px; margin-left: 300px;"></div>	<input type="checkbox"/> member <input type="checkbox"/> advisor <input type="checkbox"/> officer
2. <div style="border: 1px solid black; width: 100px; height: 20px; margin-left: 300px;"></div>	<div style="border: 1px solid black; width: 100px; height: 20px; margin-left: 300px;"></div>	<input type="checkbox"/> member <input type="checkbox"/> advisor <input type="checkbox"/> officer
3. <div style="border: 1px solid black; width: 100px; height: 20px; margin-left: 300px;"></div>	<div style="border: 1px solid black; width: 100px; height: 20px; margin-left: 300px;"></div>	<input type="checkbox"/> member <input type="checkbox"/> advisor <input type="checkbox"/> officer
4. <div style="border: 1px solid black; width: 100px; height: 20px; margin-left: 300px;"></div>	<div style="border: 1px solid black; width: 100px; height: 20px; margin-left: 300px;"></div>	<input type="checkbox"/> member <input type="checkbox"/> advisor <input type="checkbox"/> officer

CONTINUE ON NEXT PAGE

c4.

C4A.

Since <b>July 1, 1994</b> , has the DCP conducted a program or project with any of the following state agencies <b>within the Health Department</b> ? Please <b>✓ Yes</b> or <b>No</b> for each item.		If Yes, please give name or brief description of program.
<b>State Agencies WITHIN Health Department:</b>		
1. Cardiovascular Health	<input type="checkbox"/> Yes <input type="checkbox"/> No	
2. Medical Assistance Program (Medicaid Managed Care)	<input type="checkbox"/> Yes    0 No	
3. Maternal Child	<input type="checkbox"/> Yes <input type="checkbox"/> No	
4. Nursing	0 Yes    0 No	
5. Minority Health	0 Yes    0 No	
6 Smoking	<input type="checkbox"/> Yes <input type="checkbox"/> No	
7. Chronic Disease Division as a whole	0 Yes <input type="checkbox"/> No	
8. Health Department as a whole	<input type="checkbox"/> Yes    0 No	
9. Other (Specify):	<input type="checkbox"/> Yes    0 No	
<div style="border: 1px solid black; height: 20px; width: 100%;"></div> <div style="border: 1px solid black; height: 20px; width: 100%;"></div>		

c5.

C5A.

Since <b>July 1, 1994</b> , has the DCP conducted a program or project with any of the following state agencies <b>outside</b> the Health Department? Please <input checked="" type="checkbox"/> Yes or No for each item.		If Yes, please provide name or brief description of program.
<b>State Agencies OUTSIDE Health Department:</b>		
1. Education	<input type="checkbox"/> Yes <input type="checkbox"/> No	
2. Social Services	<input type="checkbox"/> Yes <input type="checkbox"/> No	
3. Youth	0 <input type="checkbox"/>	
4. Aging	0    0	
5. Minority Issues	0    0	
6 Legal Department	0    0	
7. Governor's office	0    0	
8. Legislature	<input type="checkbox"/> 0	
9 Other (Specify):	<input type="checkbox"/> 0	
<div style="border: 1px solid black; height: 20px; width: 100%;"></div> <div style="border: 1px solid black; height: 20px; width: 100%;"></div>		

## SECTION D. Advisory Structure

Questions in this section are concerned with the type of advisory structure that your DCP utilizes. The advisory structure varies from state to state and may also have varied over time. It usually consists of an advisory body and may include other structures, such as special work groups or advisors.

- D1. Please ☒ the **one** designation which best describes the advisory body your DCP now has.

- ☐ Advisory Council  
☐ Coalition  
☐ Steering Committee  
☐ Work Group  
☐ Other (SPECIFY):

--	--	--

- D2. Has the type of advisory body changed its designation since **July 1, 1994**?

- ☐ Yes  
☒ No - Skip to D3

- A. When did this change occur?

Date ..... 

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 / 

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Month Year

- B. What was the prior designation?  
**Please ☒ one response.**

- ☐ Advisory Council  
☐ Coalition  
☐ Steering Committee  
☐ Work Group  
☐ Other (SPECIFY):

--	--	--

- D3. Does the advisory body, as presently constituted, contain subcommittees or special task forces?

- ☐ Yes  
☒ No - Skip to D5

- A. Are these standing or ad hoc subcommittees or task forces?

- ☐ Standing  
☐ Ad hoc - Skip to D5  
☐ Both standing and ad hoc

**D4.** Please list the names of your **standing** subcommittees or task forces.

1.	_____			
2.	_____			
3.	_____			
4.	_____			
5.	_____			
6.	_____			

**D5.** To whom is the advisory body responsible?

Please ☒ the **one** answer that is specified in the by-laws or other documentation establishing the group.

- ☐ Governor  
☐ Legislator  
☐ DCP itself  
☐ Health officer  
☐ Not specified  
☐ Other (SPECIFY):

_____			
_____			

**A.** When was this relationship established?

Date      ..... 

--	--	--	--

 / 

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 / 

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Month                      Year

**B.** If this relationship was established after **July 1, 1994**, to whom was the group responsible **before** the change in relationship?

- ☐ Not applicable - **Skip to D6**  
☒ Governor  
☐ Legislator  
☐ DCP itself  
☐ Health officer  
☐ Not specified  
☐ Other (SPECIFY):

_____			
_____			

**D6.** Did your DCP receive CDC cooperative agreement funding during the 1989-1994 funding cycle?

- ☐ **Yes**  
☐ **No - Skip to D9**

**D7.** Since **July 1, 1994**, have any new member organizations become involved with your advisory body?

- ☐ **Yes**  
☐ **No - Skip to D8**

A. If yes, please give the names of any new organizations.

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_

**D8.** Since **July 1, 1994**, have any member organizations dropped out of your advisory body?

- ☐ **Yes**  
☐ **No - Skip to D9**

A. If yes, please give the names of the organizations that dropped out.

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_

- D9. Please provide up to three examples of activities or initiatives accomplished by your advisory body that have occurred since **July 1, 1994**. If accomplishments **have been attempted** but have been only **partially successful**, please discuss the barriers to success and any lessons learned. **Please print clearly.**

D9A. Activities Achieved or Initiated	D9B. Barriers to Achievement	D9C. Lessons Learned
1.		
2.		
3.		

**SECTION E. Strategic Plan**

*Section E asks about the strategic planning for diabetes in your state.*

**DCP Plan**

- E1. Does your DCP have its own strategic plan (other than the application for the Cooperative Agreement)? ☐ Yes ☐ No - **Skip to E4**
- A. When was the most recent DCP strategic plan completed? Date .....        
Month Year
- B. How many objectives are listed in the DCP strategic plan? # of Objectives .....
- C. Of the objectives listed in the DCP strategic plan, how many have been completed? # of Objectives Completed ..
- D. How many objectives of the DCP strategic plan are now in progress? # of Objectives in Progress ..

**If no objectives of the DCP strategic plan have been completed or attempted, please skip to Question E4.**

- E2.** For the DCP strategic plan, please provide up to three examples of objectives that were completed. If relevant, list any barriers encountered and please provide examples of the manner in which a barrier to completion of the objective was overcome. **Please print clearly.**

**E2A.****E2B.**

<b>Objectives Completed</b>	<b>If relevant, please tell us how barriers to completion were overcome.</b>
1.	
2.	
3.	

- E3. For the DCP strategic plan, please provide up to three examples of objectives that were attempted but NOT completed and the barriers that prevented their completion. **Please print clearly.**

E3A.

E3B.

Objectives NOT Completed	Barriers to Completion
1.	
2.	
3.	

<b>State Strategic Plan</b>
-----------------------------

- E4. Is there a state (not DCP) strategic plan for diabetes?
- ☐ Yes, a separate state strategic plan for diabetes
- ☐ Yes, a component of an overall strategic plan for the state
- ☐ No - **Skip to Section F**
- E5. Did the DCP provide input into the development of this plan?
- ☐ Yes
- ☐ No
- E6. Did the advisory body provide input into development of this plan?
- 0 Yes
- 0 No
- E7. When was the most recent **state** strategic plan for diabetes or diabetes component completed?
- Date ... .. 

--	--

--	--	--	--
- Month                      Year
- E8. How many objectives are listed in this plan?
- # of Objectives ..... 

--	--	--
- E9. Of the objectives listed in this plan, how many have been completed?
- # of Objectives Completed 

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E10.

How many objectives of this plan are now in progress? **If no objectives of the DCP strategic plan have been completed or attempted, please skip to Section II.**

# of Objectives in Progress

E11.

For the state strategic plan for diabetes or diabetes component, please provide up to three examples of objectives that were completed. If relevant, please provide examples of the manner in which a barrier to completion of the objective was overcome.

E11A.	E11B.
Objectives Completed	If relevant, please tell us how barriers to completion were overcome.
1.	
2.	
3.	

E12.

For the state strategic plan for diabetes or diabetes component, please provide up to three examples of objectives that were attempted but NOT completed and the barriers that prevented their completion.

E12A.	E12B.
Objectives NOT Completed	Barriers to Completion
1.	<div><div></div><div></div><div></div><div></div></div>
2.	<div><div></div><div></div><div></div></div>
3.	<div><div></div><div></div><div></div></div>

## II. SURVEILLANCE

## SECTION F: Behavioral Risk Factor Surveillance Survey (BRFSS)

- F1. Was the diabetes module included in the BRFSS in your state in 1994, 1995, and 1996, and if so, what was the sample size? **Please ✓ Yes or No for each year.**

	Yes	No	Sample Size
1994 .....	<input type="checkbox"/>	<input type="checkbox"/>	
1995 .....	<input type="checkbox"/>	<input type="checkbox"/>	
1996 .....	<input type="checkbox"/>	<input type="checkbox"/>	

- F2. What is the **next** year you expect to implement the diabetes module of the BRFSS?

Year .....

- F3. What do you anticipate the sample size will be?

Sample Size: \_\_\_\_\_

- F4. Has the DCP conducted any data collection to supplement the BRFSS in order to identify persons who have been diagnosed with diabetes but might have been missed by the BRFSS?

☐ Yes  
☐ No - Skip to F5

*If Yes, please describe in the chart below, the data collection activity undertaken to supplement the BRFSS. The first row contains a hypothetical example.*

F4A.	F4B.	F4C.	F4D
Type of Survey	Target Population	Sample Size	Purpose
Door-to-door survey	Persons below poverty level in three urban census tracts	1,000 adults	Identify persons without telephones
1. <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>			
2. <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>			
3. <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>			

F5. Does your program utilize data from the main body of the BRFSS?

- ☐ Yes  
☐ No - Skip to Section G

F6. Which of these key indicators from the main body of the BRFSS does your DCP use?

**Please ✓ Yes or No for each item.**

- | Yes                      | No                       |                  |
|--------------------------|--------------------------|------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Smoking          |
| <input type="checkbox"/> | <input type="checkbox"/> | CVD              |
| <input type="checkbox"/> | <input type="checkbox"/> | Nutrition        |
| <input type="checkbox"/> | <input type="checkbox"/> | Exercise         |
| 0                        | 0                        | Other (Specify): |

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F7. Who analyzes the data?

- ☐ DCP  
0 Another department or agency.  
Specify:

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F8. How often are the data referred to in Question F6 analyzed?

- ☐ Annually  
☐ Bi-annually  
☐ Other (Specify):

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**F9.**

**F10.**

**F11.**

Please provide up to three examples of how you have used data obtained through the BRFSS for program planning or evaluation.	Please describe any barriers to achievement you may have encountered (if relevant).	Please describe any lessons learned (if relevant).
1.		
2.		
3.		

## SECTION G: Other Data Sources

Below is a list of data sources. Your DCP may use none, a few, or many of the sources.

**INSTRUCTIONS FOR QUESTIONS GI-G2:**

Column G1: Please indicate whether your DCP uses the following data sources listed in the grid.

Column G2: For each No response in G1, **please circle the appropriate barrier code numbers in this column** (corresponding to those listed in the Barrier Codes box below). **Circle all that apply.** If a barrier is not on the list, please write it in Column G2.

**Barrier Codes**

- 1 = Source does not exist in this state
- 2 = There are legal or privacy issues barring access
- 3 = DCP does not have the funds to access this source
- 4 = Use of these data are not consistent with DCP's program objectives
- 5 = DCP does not have the staff to access this source
- 6 = Don't know how to access these data

**G1.****G2.**

Does your DCP use the following data sources?			Barrier (If applicable) Use Barrier Codes Above					
	Yes	No						
1. Hospital Discharge Data .....	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	5	6
2. Death Certificates .....	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	5	6
3. Birth Certificates .....	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	5	6
4. End Stage Renal Disease (ESRD) Registry ....	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	5	6
5. Diabetes Registry .....	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	5	6
6. Blindness Registry .....	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	5	6

G1.		G2.	
Does your DCP use the following data sources?	Yes	No	Barrier (if applicable) <i>Use Barrier Codes listed on p.22</i>
7. Health Plan Employer Data Information Set (HEDIS) . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	1 2 3 4 5 6
8. Pharmaceutical Database . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	1 2 3 4 5 6
9. Other (Specify): _____ <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	1 2 3 4 5 6
10. Other (Specify): _____ <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	1 2 3 4 5 6
11. Other (Specify): _____ <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	1 2 3 4 5 6
12. Other (Specify): _____ <input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>	1 2 3 4 5 6

## SECTION H: Dissemination and Use of Data

H1. Since July 1, 1994, has your DCP disseminated information which it collected through written reports or articles in order to effect programmatic change?

☐ Yes - Please provide up to three examples below

☐ No

☐ Pending

1. \_\_\_\_\_

\_\_\_\_\_

2. \_\_\_\_\_

\_\_\_\_\_

3. \_\_\_\_\_

\_\_\_\_\_

H2. Since July 1, 1994, has your DCP disseminated information which it collected through oral briefings or presentations in order to effect programmatic change?

☐ Yes - Please provide up to three examples below

☐ No

☐ Pending

1. \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

3. \_\_\_\_\_

\_\_\_\_\_

**Appendix C**

**Findings of Exploratory Study**

**Concerning DCPs and MCOs**

**COLLABORATIONS BETWEEN SELECTED STATE  
DIABETES CONTROL PROGRAMS AND  
MANAGED CARE PLANS**



**Birch & Davis Associates, Inc.**

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April 30, 1997

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## COLLABORATIONS BETWEEN SELECTED STATE DIABETES CONTROL PROGRAMS AND MANAGED CARE PLANS

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### EXECUTIVE SUMMARY

Managed care is dramatically altering the way the nation delivers and finances health care. In both the private and public sectors, hospitals, physicians, clinics, and other health care providers are being restructured into integrated and coordinated delivery systems. Large volumes of inpatient and outpatient services are being shifted. from expensive hospitals to less costly outpatient settings. Increased emphasis is being placed on preventive health care, primary care physicians, and case management to improve quality and contain costs. Capitation payments are displacing indemnity fee-for-service arrangements, thus changing the financial incentives to providers for rendering health care.

Managed care has spread rapidly around the nation over the past few years, albeit very unevenly among and within the States. Employers, Medicaid, Medicare, and other insurers have encouraged its growth, hoping to deflate their ballooning health care bills. **All** indications are that managed care will continue to grow and to force the restructuring of health care delivery systems. In 1995, managed care was the dominant form of health **insurance** in employment settings, as nearly 75 percent of all insured workers obtained health insurance coverage through a health maintenance organization, preferred provider organization, or point-of-service health plan.

The managed care revolution has implications for Diabetes Control Programs (**DCPs**), depending directly on the proportion of a State's population enrolled in managed care plans. In essence, by requiring an overhaul of the delivery and financing of health care, managed care challenges State **DCPs** to revise and expand their traditional ways of doing business. The new approach calls for **DCPs** to collaborate with managed care plans to prevent diabetes mortality and morbidity. Such collaborations would represent a **significant** departure from conventional public health practices.

Birch & Davis Associates, Inc. (B&D), undertook this exploratory study to document such collaborations between **DCPs** and managed care plans. Its purposes were to:

- Identify and summarize the types of collaborative projects in progress or completed
- Explain the underlying reasons for the collaborations
- Document the strategies used by the **DCPs** to build bridges to managed care plans and the latter's willingness to work with the programs
- Ascertain whether the collaborations achieved their goals

- 
- Summarize lessons the sampled programs learned that might be helpful to other DCPs beginning to collaborate with managed care plans

Section I **identifies** the State-run **DCPs** whose representatives were interviewed for this study. All of these programs are actively engaged in multiple projects to reduce diabetes mortality and morbidity. But the majority of them—including the programs in Minnesota, Oregon, and Washington, which we visited—have revised and expanded traditional public health strategies to involve managed care plans in the pursuit of public health goals. These programs are collaborating with managed care plans directly as well as indirectly through other entities, including Medicaid agencies, corporate and State purchasing alliances, and Medicare peer review organizations.

Each of the three **DCPs** we visited has collaborated with managed care plans in the development of diabetes guidelines. The programs believe that managed care plans' involvement will result in the guidelines being accepted and implemented more quickly than otherwise. Section II explains the nature, structure, and details of the collaborations, which varied by State. In Oregon and Washington, for example, the **guideline** advisory committee was convened by State representatives, whereas in Minnesota, the committee was convened by a private organization.

Development and/or implementation of diabetes guidelines is an extremely important activity of **DCPs**. However, the best guidelines are of little practical **value** unless primary care physicians use them to diagnose and treat patients. As Section III explains, **DCPs** are collaborating with managed care plans to implement diabetes guidelines as part of continuous quality improvement (**CQI**) efforts. In some collaborations, a **DCP** works directly with a managed care plan and its affiliated clinics. In others, the program collaborates indirectly through Medicaid agencies and Medicare Peer Review Organizations.

**DCPs** are always interested in locating new data sources to document and analyze **the societal** and financial burden of diabetes. Accurate data are essential for public health Policy and planning purposes. Section IV **summarizes** collaborative projects that **will** provide **DCPs** with access to new data about diabetes care management in outpatient settings. The information could serve as benchmarks to analyze the extent to which diabetes guidelines have been implemented and to identify care management processes warranting improvement.

As managed care continues to spread across the nation, additional State **DCPs will** likely want to collaborate with managed care plans to achieve public health **goals**. Section V summarizes several important lessons that the sampled **DCPs** learned **from** their collaborations with managed care plans. Section VI suggests additional ways that State-run **DCPs** and managed care plans might collaborate to reduce the burden of diabetes.

These collaborations have been neither easy nor seamless. Significant time and energy have been required for both sides to come to trust and understand each other, learn the same language, and cement productive working relationships. It has taken several months for the people involved to become comfortable with each other and function as a team with a shared commitment. Initially, there was uncertainty about how best to capitalize on each team member's strengths.

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It has not been enough for the hands-on staff to be committed to a project's success. Strong and visible support from senior administrators above the DCP level has been essential to keep the projects funded and moving along briskly.

The collaborative projects we studied seem to be working well, largely because they are staffed by persons who:

- Have the professional and technical skills to design and implement the project
- Are authorized to make important decisions rather than having to defer to senior managers
- Appreciate the commitment and resources required to implement and manage the projects
- Are able to adapt to changing situations and to readily recognize the merits of alternative approaches
- Do not rush **matters** and recognize that it takes time to win the cooperation of people with different perspectives
- Believe strongly in the collaboration's goals and really want the projects to succeed

## 1. INTRODUCTION

Managed care is dramatically altering the way the nation delivers and **finances** health care. In both the private and public sectors, hospitals, physicians, clinics, and other health care providers are being restructured into integrated and coordinated delivery systems. Large volumes of inpatient and outpatient services are being shifted from expensive hospitals to less costly outpatient settings. **Increased** emphasis is being placed on preventive health care, primary care physicians, and case management to improve quality and contain costs. **Capitation** payments **are** displacing indemnity fee-for-service **arrangements**, thus changing the financial incentives to providers for rendering health care.

Managed care has spread rapidly around the nation over the past few years, albeit very unevenly among and within the States. Employers, Medicaid, Medicare, and other insurers have encouraged its growth, hoping to deflate their ballooning health care bills. All indications are that managed care will continue to grow and to force the restructuring of health care delivery systems. **In** 1995, managed care was the dominant form of health insurance in employment settings, as nearly 75 percent of all insured workers obtained health insurance coverage through a health maintenance organization, preferred provider organization, or point-of-service health plan.

The managed care revolution has implications for Diabetes Control Programs (**DCPs**), depending directly on the proportion of a State's population enrolled in managed care plans. **In** essence, by

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requiring an overhaul of the delivery and financing of health care, managed care challenges State **DCPs** to revise and expand their ways of doing business. The new approach calls for **DCPs** to collaborate with managed care plans to prevent diabetes mortality and morbidity. Such collaborations would represent a significant departure from conventional public health practices. Numerous questions have been raised about their likely structure, content., and workability.

### 1.1 Scope and Purpose

By mid-1996, 42 States had been awarded a cooperative agreement from the Centers for Disease Control and Prevention (CDC) to establish a **DCP**. Two of these states-Michigan and Minnesota-had also received an enhanced agreement to expand the activities financed by the core agreement. Subject to Federal requirements, States receiving such funding can exercise broad discretion in developing programs to reduce the burden of diabetes and improve the quality of care provided to persons with diabetes.

This exploratory study was undertaken to learn about collaborative efforts between a sample of **DCPs** and managed care plans. B&D conducted this study for the **CDC** as a subcontractor to Battelle. The study's major purposes were to:

- Identify and summarize the types of collaborative projects in progress or completed
- Explain the underlying reasons for the collaborations
- Document the strategies used by **DCPs** to build bridges to managed care plans and the latter's willingness to work with the programs
- Ascertain whether the collaborations achieved their goals
- Summarize lessons the sampled programs learned that might be helpful to other **DCPs** beginning to collaborate with managed care plans

The study was divided into the following four major tasks, which overlapped to a certain extent:

- Select States to Study
- Conduct Telephone Interviews
- Make Site Visits
- Prepare a Report

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## 1.2 Select States To Study

Time and budget constraints caused the B&D study team to limit the study to a sample of eight States. We discussed sample selection with CDC and Battelle and considered several factors in making the final choice, including whether:

- The State had a CDC cooperative agreement to operate a DCP
- The State had recently enacted health care reform legislation that encouraged the formation of managed care delivery systems
- The State had enrolled a large number of Medicaid recipients in managed care plans
- Employers and/or public agencies were involved in purchasing health care for a significant number of people from managed care plans

Eight states were selected to represent a diversity of collaborative efforts and geographic locations. The eight States are: Arizona, California, Massachusetts, Michigan, Minnesota, Oregon, Tennessee, and Washington. Michigan and Minnesota were chosen because they are the only States with an enhanced CDC diabetes cooperative agreement. Arizona, California, Massachusetts, Oregon, and Washington were chosen because managed care plans have already captured a significant portion of their health care markets. Tennessee was selected because more than one million of its Medicaid recipients are enrolled in managed care, which is relatively new to this State.

## 1.3 Conduct Telephone Interviews

We telephoned representatives of the eight **DCPs** to introduce ourselves, explain the study, and elicit their interest in participating in a telephone interview and a possible **followup** site visit. All **agreed** to an interview at a future date. They also agreed to provide us with copies of their CDC diabetes cooperative agreement application and latest annual and quarterly reports. We reviewed these documents prior to the telephone interviews.

Each telephone interview averaged about 90 minutes. We typically spoke with two or three representatives of the DCP, focusing on their current or planned collaborations with managed care plans. We subsequently received additional documents and reviewed them.

From the interviews and documentation we learned that the sampled State **DCPs** are engaged in numerous projects aimed at reducing diabetes mortality and morbidity. Most projects involve:

- Measurement and ongoing surveillance of the societal and financial burden of diabetes
- Development and implementation of new methods to prevent diabetes complications

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- Coordination and integration of statewide efforts to attain diabetes-related public health goals
  - Other activities, e.g., advocacy for better insurance coverage of diabetes-related preventive care, supplies, and patient education

These four activities were usually being undertaken in collaboration with local public health departments, regional coordinating boards, community groups, single clinics, medical societies, and advocacy groups.

We also learned that the majority of the **DCPs**, including the programs in Minnesota, Oregon, and Washington, had expanded their rosters of collaborators to include managed care plans. In general, this expansion has occurred with the support of the senior executives to whom the **DCPs** ultimately report. The expansion has resulted in managed care plans and **DCPs** collaborating to develop the infrastructure needed to achieve mutually beneficial goals. These three programs' commitment to partnering with managed care plans is emphasized in their applications for cooperative agreements and their periodic status reports.

#### 1.4 Make Site Visits

Based on the telephone interviews and State documentation, we concluded that **five of** the sampled States were collaborating with managed care plans: Arizona, California, Minnesota, Oregon, and Washington. The remaining three States have not collaborated with or have not gone beyond taking initial steps to collaborate with managed care plans (Massachusetts, Michigan, and Tennessee).

After **further** study, we telephoned the Minnesota, Oregon, and Washington **DCPs** to request on-site meetings to broaden our understanding of their working relationships with managed care plans. Their representatives agreed to meet with us and to schedule interviews with their counterparts in the collaborating health plans and other organizations.

In a previsit letter, we reiterated our interest in joint projects between the **DCPs** and managed care plans, Medicaid managed care programs, and State purchasing alliances. From the telephone conversations, we learned that the collaborations to date had primarily involved guideline development, CQI programs, research projects, and surveillance activities.

We explored the following six topics during our site visits:

- Operational and policy changes the **DCP** had made to adapt to or shape the managed care revolution
- Methods the program used to select managed care plans for collaborative projects
- Establishment of linkages between the program and managed care plans

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- Managed care plans' interest in and views about collaborating with the DCP, as well as those of Medicaid and purchasing alliances
  - The structure, content, and details of the collaborations
  - Lessons learned or advice for DCPs wanting to collaborate with managed care plans

We made the site visits between December 11 and December 19, 1996, spending about two days in each State. We met with representatives of DCPs and chronic disease programs and with health department officials. We also met with representatives of organizations that were collaborating with the DCP, including managed care plans, State purchasing alliances, Medicaid programs, and Medicare peer review organizations.

The following questions are indicative of those we asked during our site visits:

- How has managed care affected the strategies and tactics the DCP uses to attain its goals?
- How has the DCP reshaped its strategies to accommodate the managed care revolution?
- How has the DCP selected managed care plans to collaborate with?
- How has Statewide health care reform or Medicaid's migration to managed care affected the DCP's activities?
- Have managed care plans volunteered to collaborate with the DCP?
- What factors have encouraged or hindered collaboration with managed care plans?
- Do senior executives to whom the DCP reports believe managed care has a role to play in public health?
- Are managed care plans interested in working with the DCP?
- Have competing managed care plans been willing to work together to achieve public health goals?
- Why is or is not the DCP collaborating with managed care plans?
- What working relationships exist between the DCP and Medicaid, other State programs for persons without adequate health insurance, and a State purchasing authority?

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All of the people we interviewed were assured that their remarks were not for distribution and would remain anonymous. Everyone shared their time and insights generously with us.

## 1.5 Prepare a Report

This report is based on our telephone interviews, site visits, and documents the sampled States provided to us. While it includes some information from all of the sampled States, it focuses primarily on collaborations in the three States that participated in the site visits. In addition, telephone interviews with and documents provided by the five other States are reflected in the text on lessons learned in Section 5.

A copy of the working document was forwarded for review to the eight sampled States. This report incorporates most of their comments.

## 2. DIABETES GUIDELINES

One of a **DCP's** major activities is the development and implementation of diabetes guidelines. These guidelines represent a **minimal** level of preventive health care that experts believe a population needs to prevent complications of diabetes. Diabetes guidelines are not legally enforceable practice standards, nor do they instruct physicians how to treat diabetes patients. Instead, they focus **quality** assurance on various primary care **services** (e.g., screenings and laboratory tests) that have been found to make a difference in the long-term care of diabetes patients, at least in the aggregate.

Numerous sets of diabetes guidelines have been developed by myriad public agencies and private health plans. Many of their differences represent professional differences of opinion about the reliability of the underlying scientific evidence. Multiple sets of diabetes guidelines compete with each other for a physician's or health plan's attention; they **also** compete with those for other diseases. Budget constraints **limit** the number of guidelines that any health plan or physician, can adopt at any one time.

### 2.1 Conventional Method

Diabetes guidelines have usually been developed by a committee of **specialists—e.g.,** endocrinologists, registered nurses, nutritionists, and pharmacists. Taken together, these specialists represent the DCP, local public health departments, medical societies and other associations, community groups, regional health boards, medical schools, hospitals, nonphysician health care professionals, diabetes patients, and other affected parties.

During the developmental phase of creating diabetes guidelines, experts invariably review guidelines developed by the American Diabetes Association and State **DCPs**. They also evaluate published evidence and expert opinion concerning the clinical efficacy and cost-effectiveness of alternative preventive services. Recently, they **also** began taking into account the latest diabetes performance measures in version 3.0 of the National Committee for **Quality 'Assurance's** Health Plan Employer Data and Information Set (HEDIS).

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Final diabetes guidelines *may be mailed* to **quality** improvement committees of health plans, large **clinics**, physicians, and other health care professionals. They also are disseminated through health-related organizations, State and local **health** agencies, and community groups. Convincing practitioners, clinics, and health systems and insurers, particularly those who have invested considerable time to develop their own guidelines, to implement the guidelines is a formidable task. This task is complicated by the absence of generally accepted implementation methods. Strong **endorsements** from health care leaders and organizations are relied upon to motivate quality assurance committees, physicians, and clinics to adopt the guidelines.

## 2.2 Collaborations with Managed Care Plans

The Minnesota, Oregon, and Washington **DCPs** formulated **and/or** implemented their guidelines by involving managed **care plans** in their development and/or implementation. Indeed, collaboration with these direct providers of health care was a critical component of the developmental process, one that represents a fundamental departure from traditional practice. The collaborations paralleled other notable steps the three programs have taken to partner with managed care plans.

### Motivating Factors

There are a number of reasons why the States we visited decided to involve managed care plans in activities to reach public health goals:

- Each of the three States enacted health care reform legislation in the early 1990s that emphasized the role of managed care in meeting its population's need for cost-effective health care. **Additionally**, in the State of Minnesota, health maintenance organizations are legally obligated to collaborate with public health agencies to remedy a local community's high-priority health problems.
- A significant proportion of the population in each of the three States is enrolled in a managed care plan, and most primary care physicians who practice in these States belong to at least one plan's provider network. Managed care plans in these States therefore play an extremely important role in meeting the community's need for preventive health care.
- A DCP may have wanted to **capitalize** on managed care plans' experience in treating diabetes patients or interest in developing guidelines. In such cases, the program nurtured an environment in which managed care plans and State representatives could candidly talk about guidelines and openly exchange information about disease management practices.
- Active involvement of at least some managed care **plans'** medical directors and quality improvement personnel in the developmental process was expected to result in their buying into and endorsing the guidelines, thus expediting their implementation and ongoing use.

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- Health plans that would adopt the guidelines would be likely to pay for the health services, supplies, and education programs called for by the diabetes guidelines.

In general, managed care plans were invited verbally or by mail to work with the State to develop and/or implement diabetes guidelines. Formal invitations were extended by the DCP, either in its own right or through the **office** of a senior official of the State department in which the program is housed. Invitations were extended to virtually all managed care plans or to selected (usually large) health plans based primarily on their reputation, recognized interest in diabetes prevention, previous contacts with public health agencies, and membership size.

### **Invitations Welcomed**

Most managed care plans welcomed the opportunity to work with the **DCPs**. Following are some reported reasons for their interest in guideline development and implementation:

- Collaboration was viewed as consistent with the plan's stature and position as an industry leader.
- Plan managers wanted to learn as much as possible about new ways to prevent the progression of diabetes and its complications, because diabetes is very expensive to treat.
- The plan had a research foundation that was interested in conducting diabetes-related research.
- The plan had targeted diabetes for focused review by a Medicare or Medicaid peer or external review organization and wanted to use the knowledge gained in guideline formation to improve its diabetes care management processes.
- Health plans are being evaluated by purchasers based on HEDIS measures, at least one of which relates to diabetes care.
- Plan managers **were** curious about collaborating with a public agency and wanted to stay on the proverbial cutting edge.

It is noteworthy that most clinics and primary care physicians have been very supportive of the programs' efforts to develop uniform guidelines and quality improvement processes for all diabetes patients. In practice, it is not uncommon for managed care plans to have different requirements and policies, each confident about the merits of its approach. For providers contracting with multiple health plans, conflicting requirements can be confusing and costly.

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## 2.3 Guidelines for the Sampled States

Appendices A through H contain diabetes guidelines from the eight sampled States; the guidelines differ in number, content, and specificity. For example, California's guidelines fit on a page that summarizes information most likely to be pertinent and useful to primary care physicians who, the State assumes, will consult standard references for detailed information to diagnose and treat patients. In contrast, Arizona's guidelines comprise over 13 pages of clinical notes explaining the rationale for and importance of each quality indicator.

Appendices I through K contain guideline-related information from three of the sampled States. Appendices I and J are copies of wallet-size patient health records developed by the Arizona and California DCPs respectively. These records enable patients and providers to determine quickly whether **timely** preventive care has been received. The records list the services recommended by the diabetes guidelines, indicate **treatments** the patient receives, and show the dates of service. Appendix K is a copy of the script California uses to gather information about the diabetes guidelines **being** used by managed care plans.

### Minnesota

The committee that developed diabetes guidelines that many Minnesota providers use was not convened or chaired by the DCP or any other State agency. Instead, the guidelines were developed under the auspices of the Institute for Clinical Systems Integration (**ICSI**). A nonprofit organization, **ICSI** was formed in 1993 by several purchasing groups, large physician group practices, and managed care organizations. Its primary purpose is to develop and implement guidelines to improve health care through continuous quality improvement.

The diabetes guidelines were developed by a **14-member** committee, chaired by an ICSI representative, that includes Health Partners, Mayo Clinic, Park **Nicollet Clinic**, International Diabetes Center, and Minnesota Buyers Health Care Action Group, which is a purchasing consortium of large self-funded employers in the State. They represent the 18th set of guidelines ICSI has developed. The DCP was initially invited to participate in the development of the guidelines as an observer, but at the first meeting was invited to participate as a full committee member.

The **DCP's** involvement marked the **first** time that the Department of Health was invited to participate in the development of an ICSI guideline. The invitation was facilitated by an ongoing collaborative project between the DCP and **HealthPartners**, which is a health maintenance organization with about 730,000 members. This project is a study of the impact of the guidelines and CQI processes in a number of **HealthPartners** clinics.

It is noteworthy that some ICSI members were concerned that the addition of State staff to the committee **would** add a regulatory flavor to the developmental process. Nevertheless, the program's **staff seem** to have contributed notably to the process, as suggested by the fact that the names of two of the program's representatives are listed on the guidelines cover sheet.

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The ICSI diabetes guidelines were sent for review and comment to ICSI-affiliated clinics in March 1996, along with algorithms, annotations, a companion document, and implementation and data collection plans. This information has been shared with other interested clinics and providers throughout the State.

Appendix E contains the guidelines and supporting information. The first two pages depict a decision tree or analytical framework that providers can use to evaluate and treat the targeted population, adult patients aged 18 years and over with type II diabetes mellitus. The framework consists of 25 decision steps that include recommended courses of action, references for the evidence supporting the recommendation, and population-based treatment goals. The implementation plan includes visit-specific educational objectives and diabetes education programs covered by ICSI member health plans and other programs. The measurement plan identifies the data elements that can be collected to evaluate the diabetes guidelines.

## Oregon

The State of Oregon did not have a DCP until late 1994, when CDC approved its application for a core grant. The DCP therefore had no **administrative** structure or policies in place when State health care reform legislation was enacted and its Medical Assistance Program was planning to **enroll** roughly 300,000 low-income persons in managed care plans. This represented a rare window of opportunity for the DCP to work with new delivery systems. It also explains why the program's first order of business was guideline development rather than the building of coalitions with **community**-based organizations.

The DCP established the Diabetes Guidelines Advisory Group to oversee the development of diabetes guidelines. This **15-member** group included representatives of at least three major health maintenance organizations, the **Office** of Medical **Assistance** Programs and the Oregon Medicare Peer Review Organization. The Advisory Group, through State staff and plan representatives, worked closely with a committee of medical directors of the managed care plans (nearly all health plans in Oregon) that had signed Medicaid contracts. In fact, this committee, which is chaired by the Medicaid medical director and meets regularly to discuss best practices, provided a ready, needed, and important forum for medical input into the development of guidelines.

The Medicaid committee of medical directors had significant input into the diabetes guidelines, far more than in other States, owing to the newness of Oregon's DCP. The fact that the Office of Medical Assistance Programs and the Oregon Health Division, the locus of the DCP, are housed in the same State department (Human Resources) smoothed working relationships between these committees.

Medical directors introduced the DCP to their health plans' **quality** improvement coordinators, which was important because the guidelines are being implemented as part of quality assurance and improvement programs. The DCP kept quality improvement coordinators informed of developments, actively solicited their input, and subsequently offered technical **assistance** to help them implement the guidelines. To this end, the DCP recently hired a Managed Care Coordinator to work

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with managed care plans to develop the infrastructure within managed care plans to measure and influence the level of preventive care. The position is funded half **by** the diabetes program and the breast and cervical cancer program.

Oregon's diabetes guidelines are targeted primarily at managed care plan committees responsible for measuring the performance of providers in the plan's network. This focus provides the program with opportunities to help providers build mechanisms to promote the efficacious delivery of diabetes services that their health plans are evaluating. The providers also represent a strong voice for requesting support **from** managed care plans to increase the provision of preventive diabetes care.

Appendix F contains the provisional set of Oregon's Continuous Quality Improvement Guidelines for Diabetes **Mellitus**. Issued in 1995, the set contains nine guidelines and flow sheets organized by key procedures for diabetes care. The guidelines include clinical recommendations, population-based CQI measures, and exhibits depicting clinical decision points. In some instances, the guidelines include recommended and minimal levels of treatment and recommend more aggressive therapy than is generally practiced today. Some recommendations include suggestions for implementation, and an accompanying bibliography lists studies used in developing clinical recommendations. The guidelines are provisional and will be evaluated over a one-year period. Subsequently, they will be updated to incorporate new research.

## **Washington**

In early 1996, the Washington Department of Health convened a Diabetes Outcomes Measurement Task Force to facilitate guideline development. The Task Force is co-chaired by the State's Chief Health Officer and Assistant Secretary of Health. Currently, four of the Task Force's members represent managed care plans and the health insurance industry. Four other members represent the Medical Assistance Administration (Medicaid), the State Health Care Authority, the Health Care Financing Administration, and the Washington Peer Review Organization (PRO-West). As is explained below, the first two of these agencies have helped to develop the diabetes guideline and encourage managed care plans to adopt it.

The Task Force has had spirited discussions about the number, content, and clinical efficacy of alternative guidelines as well as about data gathering requirements. The co-chairs are committed to keeping the relationship collaborative and maintaining the active involvement of managed care plans. They see themselves as facilitating guideline development, not directing it, a perspective perhaps partly shaped by the fact that in 1995, voters repealed much of the regulatory apparatus of the health care reform legislation enacted two years earlier. Efforts to avoid even the appearance of prescriptive behavior help explain why Washington's diabetes guideline is referred to as a diabetes measurement set.

The diabetes measurement set was approved by the Task Force in November 1996. As Appendix H shows, the measurement set consists of 10 clinical activities for which there is convincing evidence, including a foot exam, blood pressure testing, lipid profile development, and diabetes education. However, unlike some drafts, the approved set has no periodicity or treatment benchmarks, because

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the Task Force is uncertain of what the values should be. All participating plans, organizations, and agencies on the Task Force have been asked to **submit** their intended benchmarks for each measure. The Task Force plans to establish benchmarks and **periodicity** schedules based on its review of available information.

The Health Care Authority helps purchase managed health care for 320,000 State employees and 130,000 low-income persons ineligible for Medicaid. One of its major functions is to determine whether a managed care plan qualifies to contract with the State. Every two years, an interagency team from the Health Care Authority, the Medical Assistance Administration, and the Department of Health conducts an on-site survey to determine whether a managed care plan complies with the State's standards of care. The standards and survey instruments were developed jointly by the three agencies; they are very similar to those that the National Committee for Quality Assurance (NCQA) uses to accredit health maintenance organizations.

One requirement that managed care plans must meet is to have an active coordinated quality improvement program approved by the Department of Health. For 1997 and 1998, contracting managed care plans may also be obligated to submit two HEDIS diabetes measures to the Health Care Authority. The proposed measures are the proportion of persons with diabetes who receive a retinal eye examination during a stated time period and a measure related to the quality of diabetes secondary prevention care.

The interagency team that surveys managed care plans focuses primarily on care processes and quality improvement **activities** rather than quantitative measures per se. In other words, at this point, the team is more concerned about whether a health plan has established processes to manage diabetes effectively and collect accurate data than about the numerical values of the data. This approach enables the State to avoid imposing **unnecessary** data costs on the health plans. It stems from the fact that there are unanswered questions about the accuracy and completeness of the data that would be collected at the present time.

The information that the interagency team collects about a health plan's **quality** improvement activities is not published, because it is protected by State statute against disclosure. This statute **aims** to encourage managed care plans to work openly with the Health Care Authority to implement innovative approaches to improve the quality of care. The prospect of publication of the findings of experimental efforts could discourage managed care plans from volunteering to work with State agencies.

The Medical **Assistance** Administration has been transferring Medicaid recipients, mostly low-income women and their children, from fee-for-service medicine to managed care plans since 1994. A committee of the medical directors of the contracting health plans works to build consensus about medical and related policies. Representatives of some of the contracted plans also participate on the Task Force.

In general, Medicaid managed care plans use their own diabetes guidelines. Some may decide to select diabetes as a condition for focused quality review, especially, if the Medicaid Assistance

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Administration's proposal to transfer most aged, blind, and disabled Medicaid recipients to managed care plans is approved by the Federal Government. Health **plans** will be even more likely to adopt the guidelines if the Federal Government requires them to target diabetes for CQI.

### 3. **QUALITY OF CARE**

Many investigators have concluded that with early detection and treatment, the progression of diabetes and its complications can be prevented. These studies are the foundation of the diabetes guidelines that States **recommend** providers use to evaluate and treat diabetes patients. **DCPs** around the nation have used these studies to design and implement demonstration projects to increase the proportion of persons who receive **timely** and necessary preventive health services. Typically, a DCP collaborates with a community group, local health department, or single clinic to improve the availability and quality of preventive care.

National demonstration projects have increased the proportion of persons with diabetes who receive preventive health care. Studies have shown corresponding decreases in diabetes mortality and morbidity. Other studies have demonstrated that many diabetic patients still do not receive timely and adequate preventive health services.

#### 3.1 Collaboration with Managed **Care Plans**

Apart **from** traditional collaborations, the **DCPs** in Minnesota\_ Oregon, and Washington are working systematically with managed care plans to increase and improve the availability of services to prevent complications of diabetes. In some cases, these programs are working directly with managed care plans; in other cases, indirectly through other entities, such as Medicare peer review organizations and Medicaid programs. Their objectives are fivefold:

- Increase the volume of recommended preventive services provided to persons with diabetes
- Develop and implement a continuous quality improvement process for such services
- Identify effective care processes that managed care plans and their clinics use to ensure that persons with diabetes receive timely preventive care
- Determine the organizational and environmental characteristics within an HMO and its clinics that support or hinder CQI processes
- Develop a CQI model to export to other clinics and managed care plans

Implementation of a diabetes guideline using CQI ordinarily necessitates substantial operational changes and extra work for clinics and primary care physicians. A managed care plan's providers must therefore be convinced that the guideline and CQI processes are superior to those used currently and that the additional cost **will justify** the benefits. Resources must be committed to CQI activities,

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including baseline assessment, intervention, measurement and data collection, analysis, and feedback. In addition, diabetes-related educational materials must be developed and compiled for patients, administrative staff, and health care professionals.

The three **DCPs** we visited are partnering with a variety of managed care models with different population mixes. The more diverse the mix, the greater the likelihood that the findings from the demonstration projects can be exported to other clinics and health plans. If, instead, the projects were confined to one managed care model and one subset of the population, at least some of the findings would not be readily transferable to other clinics and other health plans.

## **Minnesota**

Minnesota's DCP is engaged in interrelated collaborative projects with three managed care plans to improve and expand diabetes preventive care. Two projects are funded under the program's core cooperative agreement; the third, under its enhanced cooperative agreement. The goals of the three demonstration projects are to:

- Identify effective ways to improve diabetes care in clinic settings through **CQI**
- Document how managed care plans work with their **affiliated** clinics to improve diabetes care and effect permanent change in care delivery
- Model the projects' **findings** and export them to other clinics in the network and to other health care systems

The projects will enable the DCP to identify ways to reduce the burden of diabetes for various populations and compare how various managed care plans work with their clinics to implement the diabetes guidelines and improve care processes. The DCP plans to factor these operational differences into its strategy to export the projects\* findings to other clinics in the State.

**Core Agreement-**The DCP is engaged in a five-year project with two relatively small **network-**model health maintenance organizations, most of whose members qualify for Medicaid, General Assistance, or **MinnesotaCare**. Both health plans have collaborated with the Department of Health on other projects.

Metropolitan Health Plan currently has about 31,000 members. It is sponsored by Hennepin County, works closely with Hennepin County Medical Center, and provides ambulatory care through a network of 38 primary care clinics. **UCare** was established by the Department of Family Practice at the University of Minnesota Medical **School**. It currently has roughly 60,000 members and contracts with 345 primary care clinics.

The DCP selected these health plans through a formal application process; they, in turn, each chose two of their **affiliated** clinics to serve as pilot sites—one residency and one community clinic. To be deemed operationally ready to participate in the project, a clinic had to demonstrate prior experience

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in conducting primary care CQI, show evidence of administrative and provider support for the project, and be providing primary health care to at least 75 Minnesotans with diabetes. In addition, clinics that had previously received funding from the DCP were not eligible for this pilot project.

The pilot clinics chose to integrate the **American** Diabetes Association's diabetes guidelines into CQI processes for diabetes patients using a Diabetes Education Resource Kit and a reference manual developed by the DCP, Diabetes and Quality Improvement: A Guide for Primary Care. Each clinic has targeted a reduction in eye disease, lower extremity problems, or other complication of diabetes. The clinics are developing a diabetes registry. A medical chart review to document baseline care patterns using a minimum set of data elements has been completed. Following are some of the data elements collected for each patient:

- **Demographic Information-Age**, gender, race, date of onset of diabetes, type of diabetes, and treatment
- **Risk Factors-Height and** weight, body mass index, history of hypertension, history of foot **ulcer** or amputation, smoking status, most recent **lipid** profile, and glycosylated hemoglobin reading
- **Preventive Services**--Date of last eye exam, blood pressure reading, foot exam results, complication-specific education, **lipid** profile, glycosylated hemoglobin test reading, dates of service, nutrition counseling, diabetes education; and outcomes

The four demonstration clinics analyzed the data, established priorities for quality improvement, and designed and implemented strategies for change. Documentation and analysis of the current processes of care have been challenging for the **clinics**. They encountered difficulties in identifying their diabetes population and in developing a registry, partly due to staffing constraints. Semiannual reports are submitted to the managed care plan which, in **turn**, submits reports to the DCP. **The clinics** receive a small stipend for participating in the project. The stipend reportedly does not cover their costs.

The managed care plans provide in-kind contributions to monitor **clinic** progress and provide technical assistance to implement quality improvement program strategies and interventions. The DCP provides the plan's implementation team with technical assistance and consultation to develop protocols, flow sheets, computer tracking systems, and CQI activities. The managed care plans provide technical assistance to their clinics in matters relating to quality improvement strategies. The managed care plans and DCP have sponsored educational programs and written materials for patients and professionals in the managed care plan and its clinics. A questionnaire is being developed to document, evaluate, and improve the collaboration process.

**Enhanced Agreement-The DCP** is engaged in a five-year collaboration project with a large mixed-model health maintenance organization. **HealthPartners** was formed in 1992 in a merger of Group Health Inc. (**primarily** a staff model plan) and **MedCenters** Health Plan (a group model plan).

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In 1994, **HealthPartners** in turn merged with Ramsey Health Care, Inc., which comprises a large urban hospital and a network of affiliated clinics.

The organization, still called **HealthPartners**, has a research component (Group Health Foundation), which conducts studies of health care outcomes and the cost-effectiveness of health care delivery. Group Health Foundation estimates that 5 percent of its members have diabetes but account for 15 percent of medical costs. A 1-percent reduction in the glycosylated hemoglobin rate (e.g., from 8.5 percent to 7.5 percent) could therefore reduce health care expenditures noticeably.

The collaboration between the DCP and **HealthPartners** evolved from at least three activities. First, **the** Director of Clinical Research at **HealthPartners** served for several years in an advisory capacity to the DCP as it developed quality improvement initiatives. Second, consistent with a Minnesota law requiring managed care plans to collaborate with **public** health agencies, **HealthPartners** targeted a reduction of 30 percent in **diabetes** complications over four years. This planned reduction was similar to the statewide target set by the Department of Health. Each entity also focused on improving services for persons with diabetes. Third, **HealthPartners** sought the advice and expertise of the DCP in pursuing its targeted reduction in diabetes complications. Specifically, **HealthPartners** requested technical assistance in needs assessments, data collection, and other areas that complemented and extended its capabilities.

The collaboration is now in its second year and is referred to as Project IDEAL-Improving Diabetes care through Empowerment, Active collaboration and Leadership. The project's goals embody its sponsors' shared interest in and strong **commitment** to reducing the burden of diabetes and improving the quality of care. **HealthPartners'** interest in diabetes at the corporate level and a similar interest on the part of several researchers at the Group Health Foundation make it a desirable collaborator for this project. Additionally, one of its researcher/clinicians is also a member of the **DCP's** steering committee.

Much of IDEAL's first year was devoted to planning the project and establishing a collaborative decisionmaking framework, **defining** roles, and delegating assignments. The collaboration has not been without problems and **frustration** over roles and responsibilities. Nevertheless, the project is moving along, with both sides committed to its success.

Chart reviews and claims and encounter data are being examined to establish current diabetes care patterns. Provider and member surveys were administered in 1995 to collect baseline information. The provider survey was sent to 246 primary care physicians, half of them in **HealthPartners'** staff model clinics and the other half in independent groups contracting with **HealthPartners**. The patient survey was mailed to about 2,000 members (split evenly between clinic types) who had been continuously **enrolled** in **HealthPartners** for one year, had **two** or more diagnoses of diabetes **mellitus** within the past year, or had a prescription for insulin or an oral hypoglycemic filled during the past year. In addition, Project IDEAL's intervention and data collection methods and tools were pilot tested in three clinics.

Six matched pairs (control and intervention) of **HealthPartners** clinics will initially participate in a

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randomized trial of diabetes interventions in a CQI environment. ICSI guidelines will be the basis for evaluating the quality of diabetes care. The DCP and **HeathPartners** are providing technical support to implement the project and train clinic staff to improve diabetes care. Clinic staff will be surveyed to assess their perception of CQI, their level of CQI training, and their use of and perception of the impact of the diabetes guidelines.

## **Oregon**

Through the Oregon Health Division, the State's DCP is collaborating with the Office of Medical Assistance Programs and county health departments to implement Project: PREVENTION! Beginning in August 1996, this project requires contracting managed care plans to focus on providing one or more specified services to Medicaid recipients.

Two health plans are focusing on diabetes. One health plan intends to develop a diabetes registry and a community-wide education program for providers who care for diabetes patients. The other health plan will focus on increasing diabetes screenings. Several other managed care plans will concentrate on reducing tobacco use, a key health risk factor for diabetes patients.

Additional Medicaid managed care plans may focus on diabetes after aged, blind, and disabled Medicaid recipients are transferred to managed care plans, scheduled to begin in February 1997. There is a higher incidence of diabetes among these recipients than among other Medicaid recipients, mostly young women and their children.

The DCP is helping the Oregon Medicare peer review organization (**OMPRO**) develop plans to review the diabetes care provided by six managed care plans with Medicare risk contractors. Each of these plans has targeted diabetes for focused review. OMPRO has reviewed the medical records of a sample of each plan's Medicare **members** with diabetes. The records spanned two years to allow flexibility in treatment schedules. The sample was weighted toward younger elderly Medicare members, focusing on preventive care rather than treatments for complications of diabetes. The findings have been incorporated into educational materials.

OMPRO is planning to use the State's diabetes guidelines to help decide which data elements to collect for its focused reviews. Pooled data will **be** used to define baseline care patterns and compare actual performance with recommended care patterns. In addition, because OMPRO will collect test values and laboratory results (e.g., blood pressure readings and lipid profiles), it will be able to determine what the performance rates would have been had the corresponding guidelines had **different recommended** values. The findings could cause the guidelines to be revised and enhance the translation of diabetes control strategies into medical practice.

The findings will be compared with those from another collaborative project of the DCP and OMPRO. Both parties have asked the Health Care Financing Administration for Medicare Part B claims data on fee-for-service beneficiaries in Oregon. The data will be used to document and analyze the delivery of selected diabetes preventive services in outpatient settings. The findings will help the

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DCP develop interventions to improve diabetes care. The findings may also be **used as** benchmarks in focused reviews OMPRO will conduct for Medicare.

The DCP is also collaborating with OMPRO to disseminate the findings of the latter's recent study of the rates at which six managed care plans provide preventive diabetes care to Medicare beneficiaries. Overall, the findings show relatively poor rates for preventive services. It is unclear, however, whether inadequate documentation significantly affected the observed rates.

Finally, the Oregon Health Division is working with Oregon Health Systems In Collaboration (OHSIC) to implement an immunization registry. OHSIC is a spinoff of the Oregon Association of Hospitals and Health Systems. One of its key objectives is to help hospitals adjust to the managed care movement by becoming efficient health care systems. Its membership includes large hospital health systems and the Oregon Health Division.

OHSIC matched its members' funds with a grant it obtained from the Kellogg Foundation to address several public health issues, including immunization, diabetes prevention, domestic violence, and teenage pregnancy. There has been some discussion of using the same mechanism to develop a diabetes registry (or even a preventive services registry, including specific diabetes-related services), but to date there has been no **agreement** between OHD and OHSIC or any development of a diabetes registry.

## **Washington**

Washington's DCP is coordinating with the PRO-West, a nonprofit organization that conducts utilization review for Medicare, and several managed care plans to document diabetes care patterns for Medicare members and establish baselines for the measurement set developed by the Diabetes Outcomes Measurement Task Force. The project calls for PRO-West to review the medical records of a sample of Medicare members **from** the five managed care plans. To define the diabetes population consistently across health plans, PRO-West will use the latest HEDIS 3.0 definition to identify members with diabetes rather than have each plan select a sample of its Medicare members with diabetes. All parties recognize that the HEDIS 3.0 definition is imperfect but nevertheless believe that it will fit a very large proportion of Medicare members with diabetes see Exhibit I.

Each health plan will select 100 records for the study. The **findings will** be distributed to the participating health plans. This will permit the participants to gauge the extent to which the guidelines have been implemented. In addition, the health plans believe that this project will provide them with more information about ways to improve the quality of care and for greater returns than they previously have gotten from Medicare's unfocused reviews.

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## EXHIBIT 1

### HEDIS 3.0 PERFORMANCE MEASURE EYE EXAMS FOR PEOPLE WITH DIABETES

The performance measure is the percentage of Medicaid, commercial, and Medicare risk members with diabetes (type I or type II) age 31 years and older who were continuously enrolled during the reporting year and who had a retinal ophthalmoscopic examination during the reporting year. Enrollees who had no more than one break in enrollment of up to 45 days during the reporting year should be included in this measure. Separate calculations are made for commercial, Medicaid, and Medicare risk populations.

Both the administrative and hybrid approaches rely on ambulatory claims and encounter data and pharmacy data to identify people with diabetes. Persons identified as diabetic are those who:

- Were dispensed insulin and/or oral hypoglycemics on an ambulatory basis during the reporting year.  
or
- Had two face-to-face encounters in an ambulatory setting OR one face-to-face encounter in an inpatient or emergency room setting with a diagnosis of diabetes.

Many health plans have a high rate of false positives when they use laboratory data to identify members with diabetes because, diabetes diagnosis codes frequently are reported for tests that rule out diabetes as a cause of a medical problem. Laboratory data should therefore not be used to identify members with diabetes.

Because the frequency of retinal screening of persons with diabetes depends on the type of diabetes and the presence and severity of retinopathy, not every health plan will have a screening rate of 100 percent for a reporting year. Ideally, the screening rate should be tabulated according to risk for developing vision-threatening retinopathy. In 1997, the National Committee for Quality Assurance will investigate the feasibility of collecting the data in this manner.

Source: National Committee for Quality Assurance.

Reflective of the project's collaborative nature, PRO-West will soon mail to physicians a letter displaying the logos of all of the participating managed care plans. The letter will be signed by each plan's medical director. This collective endorsement is suggestive of the project's importance and is expected to increase physician participation.

Because the participating managed care plans compete with each other for new members, the project requires a high degree of trust and commitment from the participants to work well. Each participating plan will have access to all findings. However, the plans have signed an agreement to keep the findings confidential and not use them in advertisements. The Health Care Financing Administration strongly supports this arrangement.

#### 4. DIABETES SURVEILLANCE SYSTEMS

The States rely primarily on four data sources to measure the burden of diabetes: hospital discharge abstracts, the diabetes module in the Behavioral Risk Factor Surveillance Survey (BRFSS), birth and death records, and special studies of high-risk populations. DCPs are continuously on the lookout for new data sources to measure the prevalence and burden of diabetes in the State's population. Complete and accurate data are essential for public health policy decisions.

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To better characterize the burden of **diabetes**, some of the sampled **DCPs** (e.g., California, Massachusetts, and Michigan) have added a few **questions to those in the** BRFSS diabetes module. And one other **State** (Arizona) is exploring whether to expand the sample to include a preset number of Medicaid managed care plan members with diabetes.

#### **4.1 Collaborations with Managed Care Plans**

Many managed care plans are constructing sophisticated databases of encounter and claims data for inpatient and outpatient care, including information on prescribed drugs and laboratory services. Some larger health plans have already developed diabetes registries and are using electronic records to ensure that members receive timely preventive care.

**DCPs** recognize that managed care plans have a significant volume of information about the health care provided to diabetes patients and persons at high risk for diabetes. This is particularly true with respect to preventive care provided in outpatient settings, where fragmented delivery systems have greatly complicated or even precluded the construction of complete and accurate data sets.

The Minnesota, Oregon, and Washington **DCPs** are working with managed care plans to develop what can be described as a diabetes registry, although the terminology is not always used because of the mixed connotations of a registry to various groups. They also are working with Medicaid agencies and Medicare peer review **organizations** to obtain information about the preventive services that diabetes patients in managed **care** plans receive in ambulatory settings.

##### **Minnesota**

One way that a Minnesota HMO can fulfill its legal obligation to contribute to the achievement of public health goals is to collaborate with public agencies to strengthen population health assessments at the local, regional, or State level. To meet this obligation, a managed care plan is free to:

- Restructure its information system to collect and process data pertinent to specific public health problems
- Participate in the development of specific uniform data sets or assessment tools
- Assist in the development and implementation of assessment tools
- Help develop a statewide population-based morbidity data set

The Minnesota **DCP's** collaborations with three managed care plans to improve the quality of diabetes care all involve the collection of data for public health goals and the evaluation of diabetes guidelines. For Project IDEAL, a distinct surveillance and data review subcommittee was created to design the project, select the research methods, and interpret and distribute the findings.

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The DCP has been working with the Foundation for Health Care Evaluation-the Minnesota Medicare Peer Review Organization-to document and analyze the rate of diabetes-related hospitalization among Medicare beneficiaries. They also plan to review and analyze the utilization of outpatient diabetes services in the fee-for-service sector when the data become available.

## **Oregon**

The Oregon Medical Assistance Program has agreed to provide the State's DCP with access to the encounter data that Medicaid managed care plans are contractually obligated to submit on their Medicaid members. Research analysts at the Health Division are developing the expertise needed to access the data and calculate population-based measures.

Person-level encounter data elements recorded include demographic information and International Classification of Diseases, 9th Edition, Clinical Modification and Physicians' Current Procedural Terminology codes. This **information** will enable the researchers to identify diabetes patients and the types, volume, and periodicity of the services they receive. Medicaid data may also play a role in designing and focusing the reviews that will be conducted by Medicaid's external quality review organization.

## **Washington**

Managed care plans in Washington are contractually obligated to provide the Medical Assistance Administration with person-level encounter data for Medicaid members. The data could be used to conduct studies to quantify and examine care in outpatient settings for low-income diabetes patients as well as hospitalizations associated with diabetes.

Given this new data source, the DCP could generate information county by county showing the number of low-income persons with diabetes in Medicaid managed care plans, the proportion of Medicaid members with diabetes who receive preventive care, and the proportion of hospitalizations for diabetes-related conditions. These data could be incorporated into State and local community health assessments.

## **5. LESSONS LEARNED**

DCPs in most of the sampled states are working with managed care organizations to prevent diabetes and its complications. The scope and extent of the collaborations vary, partly because of interstate differences in the proportion of the population **enrolled** in managed care plans. Almost certainly, more DCPs will form working relationships with managed care plans as managed care expands in other States.

In general, the visited DCPs believe in the potential effectiveness of collaborating with managed care plans. These States are committed to working with managed care plans and have implemented several projects to do so. These projects complement other collaborations with local health

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departments, regional boards, and **various** community **groups** that also **are** aimed at reducing diabetes mortality and morbidity.

This section summarizes several important lessons that the sampled **DCPs** and managed care plans we visited have learned **from** their collaborations. Our summary was distilled from conversations with representatives of the eight **DCPs** and managed care plans we interviewed and documents we reviewed for this project. Although details and circumstances will probably vary, the lessons from the sampled programs and plans may help programs in other States partner successfully with managed care plans.

## **5.1 Why Collaborate?**

For at least six reasons, the sampled State **DCPs** believe that they will obtain their objectives faster by working with managed care plans:

- Managed care plans' commitment to preventive health care makes them receptive to collaborating on diabetes guidelines using continuous quality improvement processes.
- As coordinated health systems, managed care plans can influence the practice patterns of significant numbers of primary care physicians and clinics.
- Managed care plans that invest monetarily and emotionally in the development of public health diabetes strategies are more likely to hold their providers accountable for implementing those strategies.
- Managed care plans that help develop diabetes guidelines are more likely than are other health plans to pay for the services, supplies, and education programs that are required to implement the guidelines.
- The results of a successful project with some clinics in a managed care plan's network can be applied to other clinics much faster than when projects are undertaken with independent clinics.
- Managed care plans have the resources to keep successful demonstration projects in place after the project's funding lapses.

## **5.2 How Did the Collaborations Start?**

A DCP, a managed care plan, or a third party may initiate a specific collaboration. Most of the collaborations we studied began in one of the following ways:

- A DCP invited managed care plans to collaborate for specific purposes, perhaps based on previous working relationships (e.g., tobacco use cessation or cancer screening programs) or the plans' known interest in the subject matter. Invitations

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were mailed or extended by telephone. In some cases, an invitation to serve on a committee or task force helped to make introductions and cement working relationships.

- A DCP issued a request for proposals or a request for applications to all managed care plans or all plans that met certain requirements. The formal request was preceded by a request for comments on a draft proposal. The comment period allowed both sides to learn their respective goals and become acquainted: it helped set the foundation for working with successful offerors. The availability of financial support was an important factor in attracting managed care plans, even though the amounts were small and may not have covered total costs.

In preparing a solicitation, program staff had to walk a narrow line when specifying a project's requirements, **timelines**, and deliverables. Too little specificity could have caused managed care plans to underestimate the project's requirements, leading to unhappy partners later. Too much specificity could have been interpreted as heavy-handed, causing managed care plans not to apply for the project.

- A managed care plan asked a DCP for help in performing needs assessments, developing guidelines, developing measurement tools, and improving the quality of care. The program **staff's** recognized expert& and potential for contribution to a joint effort were instrumental in motivating the managed care plan to seek its assistance.
- A third party brought a DCP and managed care plans together to work on a project. For example, a Medicare peer review organization may spearhead focused reviews calling for all three parties to work together to determine baseline patterns of preventive care for diabetes patients.

### 5.3 Has Collaboration Been Easy?

Collaborations between the sampled **DCPs** and managed care organizations have been neither easy nor seamless. Significant time and energy have been required for both sides to trust and understand each other, learn the same language, and cement productive working relationships.

It has taken months of working together for the people involved to become comfortable with each other and function as a team with a shared commitment. Initially, there was uncertainty about how best to capitalize on each team member's strengths.

Considerable **time** has been required to define each side's role in a project and establish productive working relationships. In the case of diabetes guidelines, 9 to 12 months were required to build consensus among competing health plans with conflicting views about the clinical efficacy and **cost-effectiveness** of alternative diabetes preventive services and the numerical targets to assign to population-based benchmarks.

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## 5.4 What Makes a Collaboration Work Well?

For a collaboration to work well, it has been absolutely essential for the persons who staff the project to:

- Have the professional and technical skills to design and implement the project
- Be authorized to make important decisions rather than having to defer to senior managers
- Appreciate the commitment and resources required to implement and manage the project
- Be able to adapt to changing situations and readily recognize the merits of alternative approaches
- Not rush matters and recognize that it takes time to win the cooperation of people with different perspectives
- Believe strongly in the collaboration's goals and really want the projects to succeed

It is not been enough for the hands-on **staff** to be committed to a project's success. Strong and visible support from senior administrators at a level above the DCP and in the managed care organization have been essential to keep the project funded and moving along briskly. Key senior managers have endorsed the projects and been kept informed of developments. Their input has been solicited regularly.

Some form of hierarchical structure must be established for a collaborative project to work well. At the outset, confusion and **frustration** arose over how to make decisions jointly without either party's being in charge. Formation of such a structure was time consuming and reduced progress to a frustratingly slow pace. Slowly but surely, however, workable hierarchical structures have evolved, partly because the parties **are firmly** committed to the project's goals.

## 5.5 Do Managed Care Plans Really Want To Collaborate?

Several managed care plans welcomed the opportunity to work with **DCPs**, convinced that there was much to gain from jointly tackling this costly disease. Others followed suit as word spread that the projects were truly joint efforts rather than perfunctory or politically motivated initiatives.

Managed care plans with relatively large numbers of members with or at high risk for diabetes were **prime** candidates for collaborations because diabetes was generating a disproportionately large share of their medical costs. These organizations believed that a project's financial benefits would justify its cost, although not necessarily in the short run. Also likely to be interested in collaborating on diabetes-related projects are managed care plans that have targeted diabetes for focused quality

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reviews by Medicare or Medicaid peer review organizations. Knowledge gained through these collaborations may be **transferrable** to other diseases.

## 5.6 What Factors May Hinder Collaboration?

We found that managed care plans were willing to sit down and work toward the common public health goal of fighting diabetes. However, their willingness to share information may be constrained by the fact that they compete for the **same** customers. Certain proprietary information may therefore not be available for achieving a project's goals if managed care plans believe that the findings will be made public.

We also found that the possibility of negative publicity can temper a managed care plan's interest in participating in projects to study the clinical efficacy of alternative quality improvement strategies. Public disclosure of the findings could have adverse **financial** consequences. For example, a managed care plan whose diabetes care management program is praised publicly could incur large losses if its **capitation** rates were not increased to cover the costs of **serving** the large number of sick persons who might enroll after the results were published.

Knowing that its encounter information is inaccurate or incomplete might dissuade a managed care plan from making its databases available for research studies. The plan might worry that publication of flawed data, even with appropriate **qualifiers**, could cause its **enrollment** to drop noticeably. A plan might also be concerned about its potential ranking and thus not want to be compared with other health plans.

Financial realities limit the number of projects that a managed care plan can conduct at any given time. To structure its priorities, it will weigh the estimated costs of a diabetes project against the expected gains. Depending on the plan's needs, diabetes-related projects may rank substantially lower than projects for other diseases or diabetes-related projects for preventive services may rank lower than projects focusing on secondary complications.

## 5.7 How Were Competing Proposals Evaluated?

Multiple managed care organizations responded to requests for proposals/applications. The **DCPs** developed criteria to determine each plan's readiness to participate in and commitment to the project. In reviewing responses, program staff paid special attention to:

- Whether the proposed project leader(s) had a special interest in diabetes and would be motivated to champion the project, not treat it as just another job or source of funding
- Whether the plan's proposal or application presented a clear vision of the strategies and interventions that **would** be used to identify and care for the intended populations

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- The resources the health plan was willing to commit to the project, including in-kind contributions
  - The depth of the applicant's apparent understanding of the project's time requirements
  - Whether the application included a plan to evaluate the project and transfer findings to other clinics in the network

Additionally, more than one person at each organization had to be committed to the project to prevent staff turnover **from** delaying implementation unreasonably. Information systems and data collection capabilities had to be in place to schedule appointments, track referrals, and gather and centralize information for project evaluations. Resources had to be available to educate patients, health care professionals, and clinic staff. Ideally, the managed care plan financed in-service education and training sessions and informational materials.

## 5.8 Have the Collaborations Been Successful?

The **DCPs** and managed care plans have worked together successfully to develop and implement diabetes guidelines. The effectiveness of the other collaborations is being evaluated. Demographic, structure, process, and outcome data are being collected, and the accuracy and completeness of baseline information are being assessed. Evaluative methods are being designed, often by modifying the research methods suggested in requests for proposals/applications.

In some initial evaluations, the collaborations themselves will be examined. The goals are to identify the factors that make for a good collaboration and find ways to improve working relationships between **DCPs** and managed care plans. In other initial evaluations, they will analyze how care processes are structured. For example, they **will** look at steps the plans and their clinics have taken to improve care processes, including perhaps the steps taken to develop diabetes flow sheets, implement a computerized diabetes registry, and establish a database to monitor care patterns.

In subsequent evaluations, program staff may determine whether the projects have resulted in more preventive services for diabetes patients and a reduction in the incidence and complications of diabetes. Later evaluations may address the effect of the project on health status, such as reductions in blood pressure. All parties caution, however, that outcomes studies will be complicated by numerous confounding events and will not be feasible in the short run.

## 6. CONCLUSION

Managed care is spreading rapidly and soon will probably be the dominant form of health care delivery in the more populous areas of the nation. Like State-run **DCPs**, many managed care plans are convinced that primary care services can prevent complications from and reduce the financial

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burden of diabetes. Both the programs and plans therefore have a common interest in working together to provide diabetes patients with necessary health services. Health promotion activities are especially fertile areas for collaboration.

The collaborations we studied focused largely on the development and implementation of diabetes guidelines. This initial emphasis is not surprising in light of the important role that guidelines can play in helping diabetes patients receive timely primary and preventive care. Indeed, this importance suggests that these collaborations will be replicated in other States, although the specific details may vary for assorted reasons.

Some State **DCPs** and managed care plans may decide to collaborate in other ways. One possible project would focus on modeling how managed care plans work with pilot clinics to implement diabetes guidelines using CQI processes and transferring the findings to other clinics in a managed care plan's network. Other possibilities include joint outreach programs, consumer and provider education programs, development of diabetes registries, data sharing to document the burden of diabetes and analyze the effectiveness of alternative preventive services, and the cosponsorship of professional conferences. Successful collaborations almost certainly will result in persons with diabetes being better off than if either the State DCP or managed care plans had acted alone.



**Battelle**

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